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ABSTRACT

This document presents the New Jersey statewide plan for combating the Acquired Immune Deficiency Syndrome (AIDS) epidemic. Ten recommendations of the New Jersey State Commissioner of Health focus on such issues as public/private partnerships, protecting confidentiality, and fighting discrimination. The introduction notes that the plan is driven by several themes: the need for a more structured system for delivering coordinated services for persons with Human Immunodeficiency Virus (HIV) and AIDS; the realization that the epidemic has exposed major deficiencies in our health care system; the need to more effectively address special populations at high risk for HIV/AIDS; the intention to increase the utilization of community-based services and organizations; and the realization that HIV/AIDS is increasingly becoming a disease affecting entire New Jersey families. The methodology for this state plan is discussed, and a profile of the HIV/AIDS epidemic in New Jersey is presented. New Jersey's response to the epidemic is examined from the first cases of AIDS, which were diagnosed in 1980, through 1990. The emergence of private initiatives and the state government response are reviewed. The economic cost and the human cost of HIV/AIDS are examined, and the statewide plan for the 1990s is presented. The complete list of recommendations and implementation strategies, as well as background discussions on the HIV/AIDS-related issues that produced them are presented and discussed. A section is also included on financing the plan. Supporting materials are contained in appendices. (LLL)

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NEW JERSEY:

A STATE ORGANIZING TO FIGHT AIDS

Recommendations of
State Commissioner of Health
Frances J. Dunston, M.D., M.P.H.
to
Governor Jim Florio

January 31, 1991

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NEW JERSEY DEPARTMENT OF HEALTH
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NEW JERSEY: A STATE ORGANIZING TO FIGHT AIDS

A Plan For The 1990's

Jim Florio
Governor

Frances J. Dunston, M.D., M.P.H.
State Commissioner of Health

STATE OF NEW JERSEY
DEPARTMENT OF HEALTH
CN 360
TRENTON, 08625-0360

FRANCES J. DUNSTON, M.D., M.P.H.
COMMISSIONER

(609) 292-7837

January 31, 1991

The Honorable Jim Florio
Governor
State of New Jersey
State House
Trenton, New Jersey 08625

Dear Governor Florio:

It is with a sense of satisfaction that I transmit to you "New Jersey: A State Organizing to Fight AIDS," the response of the State Department of Health to your call for a comprehensive plan to confront the HIV/AIDS epidemic in our state. It incorporates the "Ten Principles for Fighting AIDS" you enunciated in October, and offers, to borrow language from the document, "a blueprint for action intended to take New Jersey forward to the year 2000 as a state organized to fight AIDS."

This plan is the product of the most diligent labor on the part of the staff of the Department's Division of AIDS Prevention and Control and of the three working committees formed to draft recommendations for my consideration: the Departments of the State of New Jersey Advisory Committee, the Department of Health Advisory Committee, and a broad-based Community Advisory Committee. It also reflects the testimony presented at the four public meetings held across the state to solicit input and insight. Those who spoke at these meetings, along with the members of the three committees, represented the broadest range of expertise in, and involvement with, the HIV/AIDS epidemic in New Jersey.

In your October address, you called HIV/AIDS "a community disease" that demanded a response from the entire New Jersey community. I believe this plan to be such a response. And I would like to take this opportunity to thank all who worked so hard and long in its formulation. They have performed a great service.

With best wishes,

Frances J. Dunston M.D.

Frances J. Dunston, M.D., M.P.H.
State Commissioner of Health

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GOVERNOR JIM FLORIO'S PRINCIPLES FOR COMBATING AIDS IN NEW JERSEY

October 11, 1990
Atlantic City, New Jersey

ONE: GETTING THE MESSAGE OUT

"AIDS is a preventable disease. You can protect yourself. We need to get the word out. Sometimes the message will have to be hard-hitting and explicit. It won't always be comfortable. But then again, AIDS isn't comfortable."

TWO: PUBLIC/PRIVATE PARTNERSHIPS

"Tackling AIDS is not just a job for public health professionals. We need a public/private partnership. We defeated polio by mobilizing business leaders, clergy, doctors, educators and civic groups. We all must work shoulder to shoulder again. If we don't, the disease will have a serious impact on our work force, making it difficult for our businesses to compete."

THREE: PROTECTING CONFIDENTIALITY

"We must protect the confidentiality of everyone who is tested for AIDS. Early detection of HIV is imperative, not only to treat the infected person but to prevent the spread of the disease. But people won't get tested if they don't have complete confidence that those tests will be confidential."

FOUR: FIGHT DISCRIMINATION

"We can't tolerate discrimination against those with AIDS or their families, whether in jobs, housing, education, insurance or access to health care."

FIVE: PROVIDE AFFORDABLE DRUG TREATMENT AND COUNSELING

"We must understand that AIDS and all kinds of drug use, not just intravenous, are closely tied together. Fighting AIDS means providing affordable drug treatment and counseling that emphasizes the dangers of AIDS. We must also continue our efforts to educate young people in school about drugs, including in that message the link to AIDS. They should know that you don't just get AIDS from shooting up. Mood altering drugs which affect judgment, especially when it comes to protecting yourself and your partner, are also facilitating the spread of AIDS."

GOVERNOR JIM FLORIO'S PRINCIPLES FOR COMBATING AIDS IN NEW JERSEY

SIX: EXPANDING PRIVATE AIDS CARE

"We need to expand AIDS treatment so we don't rely on publicly funded programs alone. The considerable talents of our private physicians will also help. The emphasis of treatment should be on family-centered care programs which keep people independent and out of the hospital for as long as possible. Not only is this the best kind of care, it's the most economical. We also need to keep in mind that the AIDS crisis is closely tied to our health care cost crisis. And that a solution for one must address the problems of the other."

SEVEN: BETTER EDUCATION AND TESTING FOR PRISON INMATES

"We must educate those in prison about the dangers of AIDS and provide them with access to HIV testing. Many are at risk because of past drug use. By educating them we will help them return to society and take responsibility for their lives."

EIGHT: COORDINATE STATE EFFORTS

"Different parts of state government must coordinate their efforts to combat AIDS. We will set up an interdepartmental group of Cabinet officers to ensure the broadest diffusion of AIDS prevention and care efforts."

NINE: HELP PROTECT THOSE ON THE FRONT LINE

"We must help those who help those with AIDS. Health care providers, emergency, fire and law enforcement officers all give generously of themselves. They need accurate information as to how to protect themselves, the last training to treat those with AIDS, and the resources to give the quality of care they have been trained to provide."

TEN: BE RESPONSIBLE

"Everyone has an individual responsibility to prevent the spread of this disease. Act on the information that's available. If you believe you're at risk, get tested."

NEW JERSEY:

A STATE ORGANIZING TO FIGHT AIDS

A Plan for the 1990's

EXECUTIVE SUMMARY

INTRODUCTION

In October 1990, Governor Jim Florio issued 10 principles for fighting the HIV/AIDS epidemic in New Jersey. He also asked Health Commissioner Dr. Frances J. Dunston to prepare a comprehensive statewide plan for combating the epidemic.

The plan which follows incorporates the Governor's 10 principles and is driven by several themes: the need for a more structured system for delivering coordinated services for persons with HIV/AIDS; the realization that the epidemic has exposed major deficiencies in our health care system; the need to more effectively address special populations at high risk for HIV/AIDS; the intention to increase the utilization of community-based services and organizations; and the realization that HIV/AIDS is increasingly becoming a disease affecting entire New Jersey families.

The HIV/AIDS epidemic has hit New Jersey very hard. Last November, New Jersey recorded its 10,000th AIDS case. As many as 40,000 or more New Jerseyans are infected with HIV. New Jersey's epidemic is unlike that of many other states because over half of its people with AIDS are intravenous drug users, who are not easily reached by prevention/education programs. New Jersey ranks third among states in the number of women and children with AIDS; of all groups with AIDS in the state, the fastest-growing is women of childbearing age.

New Jersey has done a good deal to combat the epidemic since it began a decade ago. Some of its initiatives are national models. The Treatment Assessment Program (TAP) points the way to the future of HIV/AIDS care, with early intervention to mitigate symptoms and prolong life. New Jersey also pioneered case management--so necessary in the face of an epidemic which places such diverse demands on the entire health care and social services system.

Nevertheless, much remains to be done. It is clear that New Jersey's HIV/AIDS effort needs to be better coordinated if it is to deliver critical services efficiently and cost effectively to people with HIV/AIDS. This report offers a comprehensive blueprint for this improved coordination.

Dr. Dunston's plan, incorporates several far-reaching recommendations and proposes strategies to realize them. It also includes an epidemiologic profile of the HIV/AIDS epidemic in New Jersey, a discussion of the state's response to date, an assessment of both the economic and human cost of HIV/AIDS, and a plan of action detailing specific short- and long-term measures necessary to confront it.

This report is the result of a collaborative effort by the Department of Health, the other departments of state government involved in HIV/AIDS-related activities, and a committee of citizens concerned and knowledgeable about the epidemic. Four public meetings were also held throughout the state.

METHODOLOGY

Because the problems posed by the HIV/AIDS epidemic are so complex and diverse, both Governor Florio and Commissioner Dunston realized that the development of a state plan would require the broadest possible range of expertise. Accordingly, a decision was made to create three working committees which would meet concurrently. Each was charged with developing a set of recommendations for consideration by the Commissioner of Health. The committees were::

- the ***Departments of the State of New Jersey Advisory Committee,*** composed of the commissioners of the state departments with HIV/AIDS-related activities;

- the ***Intradepartmental Advisory Committee***, composed of the assistant commissioners who head the several divisions of the Department of Health; and

- the ***Community Advisory Committee***, composed of more than 40 individuals--legislators, health officers, care providers, members of community-based organizations and AIDS advocacy groups, and concerned individuals--including people with HIV/AIDS.

The three committees met separately for several weeks, and each was presented with the minutes of the meetings of the other two. They also were given transcripts of the proceedings of four public meeting

held throughout the state. The committees then met in plenary session to review all recommendations. Staff of the Division of AIDS Prevention and Control, in consultation with the Commissioner of Health, prepared the final report for submission to Governor Florio.

A PROFILE OF THE HIV/AIDS EPIDEMIC IN NEW JERSEY

Over 10,000 residents of New Jersey have contracted AIDS since the beginning of the epidemic; 30,000 to 50,000 more are infected with HIV. New Jersey is fifth among all states in cumulated AIDS cases, and no end to the epidemic is in sight. Some other considerations:

- Unlike most of the rest of the country, the majority of New Jersey's cases of AIDS are found among intravenous drug users (IVDUs). Many of their sexual partners and children are also infected.

- The New Jersey HIV/AIDS epidemic has struck women harder than almost anywhere else. Women account for 23 percent of the state's cases, compared with 11 percent nationally.

- New Jersey's epidemic hits minorities disproportionately. Two-thirds of the state's AIDS cases are Blacks and Hispanics who are only 19 percent of the population.

- New Jersey has 10 percent of the nation's pediatric AIDS cases which places the state third in the United States in cases among children.

- People with HIV/AIDS live in every county in the New Jersey. But the overwhelming majority of these people live in the inner cities of the northeastern part of the state.

THE NEW JERSEY RESPONSE THROUGH 1990

The first cases of AIDS in New Jersey were diagnosed retrospectively in 1980. It gradually became apparent that, although the national concentration of AIDS cases was among gay men, New Jersey's epidemic was striking large numbers of IVDUs. In 1983, Dr. Jim Oleske, a Newark pediatrician and researcher, first documented AIDS cases in children.

As in most of the rest of the United States, New Jersey state government responded rather slowly to this new public health threat. But in 1984, the State Legislature passed the AIDS Assistance Act, requiring the Commissioner of Health to establish programs to deal with AIDS education, testing and counseling, and treatment.

The Emergence of Private Initiatives

As the state began to gear up to confront what was becoming an epidemic, community-based organizations such as the Hyacinth Foundation began to provide services to people with AIDS. The Robert Wood Johnson Foundation awarded $17.2 to the state in 1986. This grant focused on the development of a case management system, and gave the state's HIV/AIDS effort its first significant financial boost. Community-based HIV/AIDS health and support service providers now number in the dozens. Many of them are staffed with volunteers, who give of themselves selflessly to "make a difference" in the fight against HIV infection and AIDS.

State Government Response: The Department of Health

At the outset of the HIV/AIDS epidemic, the Department of Health's activities were concentrated in the Division of Epidemiology and Disease Control. As more and more cases were documented among IVDUs, HIV/AIDS-related activities were gradually transferred to the Division of Narcotics and Drug Abuse. In September 1988, a new division--AIDS Prevention and Control--was created to coordinate all the Department's HIV/AIDS-related activities. The division budget for FY 91 is $27,961,000. The division is divided into the following six units:

- Care and Treatment
- Prevention/Education
- Epidemiological Services
- Medical Research
- Data Analysis
- Administration

The Department of Health's HIV/AIDS-related initiatives since 1984 include:

- one of the first seroprevalence surveys of IVDUs, in 1984;
- the implementation of blood bank screening of donated blood, in 1985;
- the opening of the first HIV/AIDS counseling and testing sites, in 1986;
- the opening of St. Clare's Home for Children in Elizabeth, in 1987;
- the opening of the Wanaque Convalescent Center to AIDS patients, in 1988;
- the creation of the Treatment Assessment Program of early intervention care and treatment, 1989; and
- the funding of one of the first perinatal AIDS programs in the country, in 1990.

It should be noted that five of the Health Department's other divisions are very involved in HIV/AIDS activities. These activities are discussed in detail in the full report. The FY91 amount budgeted for HIV/AIDS-related activities of the several divisions of the Department of Health is $34,833,000.

State Government Response: Other Departments

Three other departments of New Jersey state government--Corrections, Education, and Human Services--have specific, budgeted HIV/AIDS-related activities. Most other departments handled issues related to the epidemic as part of normal business. One benefit accruing from the planning process for this report was a realization of the potential for more effective interagency coordination of HIV/AIDS-related activites.

The FY91 total budgeted for the four departments with dedicated HIV/AIDS activities was $75,113,000.

THE ECONOMIC COST OF HIV/AIDS

The economic cost of the HIV/AIDS epidemic is very high--and difficult to estimate. Cost-of-care projections depend upon precise estimates of the number of individuals infected, the severity of their illness, survival time, and other factors.

Despite the shortage of data, attempts have been made to calculate the cost of care for HIV/AIDS patients. One study estimates the lifetime cost of care for an AIDS patient at more than $42,000. Some estimates are considerably higher. If this amount is multiplied by the number of diagnosed cases of AIDS in the United States, the price tag for their care is in excess of $6.6 billion. It should be noted that early intervention with life-prolonging drugs is increasing survival time, and is likely to increase the cost of care.

The HIV/AIDS epidemic has created difficulties for New Jersey hospitals. Until 1989, there were no Diagnosis Related Groups for HIV/AIDS. This meant that patients were assigned a DRG corresponding to the specific medical problem they presented on admission. Because HIV-infected patients tended to consume more hospital resources, hospitals lost money on these patients. This problem was somewhat alleviated when 12 HIV/AIDS-related DRGs were created in 1989. Because so many HIV/AIDS patients are indigent, however, a strain was placed on the state's Uncompensated Care Trust Fund. The total 1989 hospital bill for HIV/AIDS patients was over $70 million.

The cost of HIV/AIDS care is also a major concern for insurance carriers, and for private businesses already stretched to provide health care benefits for their employees.

THE HUMAN COST OF HIV/AIDS

This epidemic has exacted an uncalculable human toll on the infected, as well as on their friends and families. No one is in a better position to communicate the anguish of AIDS than those who have been stricken. The stories of four of them are presented in this report.

NEW JERSEY: A STATE ORGANIZING TO FIGHT AIDS/ A PLAN FOR THE 1990'S

The HIV/AIDS epidemic presents some bleak prospects for New Jersey. Last November the state recorded its 10,000th AIDS case, and many more thousands are HIV-infected. No vaccine or "cure" for HIV/AIDS is in sight. Strides are being made in early intervention drug therapies, but as this humanely extends and improves the lives of the infected, it costs an already overburdened health care system more money. There is no concerted, coordinated, comprehensive and cost-effective approach to the delivery of the broad array of health care and social services needed by people with HIV infection and AIDS. A good deal has been done to counter AIDS in New Jersey, but too often the state's programs and activities have lacked organization and cohesion.

We must continue, therefore, to do the things that have been done--tracking the epidemic, attempting to slow the rate of HIV infection, and providing care and treatment for the stricken--but we must do them better than in the past. Even more importantly, in this time of fiscal constraint we must ***evaluate and coordinate*** what we are doing more effectively to ensure that we maximize our limited resources.

This report contains a set of recommendations, and strategies to implement each of them; taken in full, they constitute the Department of Health's response to Governor Florio's October request for a comprehensive, statewide HIV/AIDS plan. The complete list of recommendations and implementation strategies, as well as background discussions on the HIV/AIDS-related issues that produced them, are contained in the full report. They fall into the following four categories of activities:

I. Improving Our Ability to Identify Those Who Are Infected

II. Slowing the Spread of HIV/AIDS

III. Delivering HIV/AIDS Care and Treatment Services

IV. Coordinating and Evaluating HIV/AIDS-Related Services

* * *

I. Improving Our Ability to Identify Those Who Are Infected

Although we do not yet have either a cure or a vaccine for HIV/AIDS, early-intervention therapy now makes it possible to improve and extend the lives of the HIV-infected. To do this, however, we must increase our knowledge of the epidemic by determining who is infected, or at high risk for infection, and how the disease presents itself in those who are infected. This is accomplished through HIV testing and reporting, seroprevalence studies, and research into education and prevention strategies, new treatment methodologies, and drug therapies. Also essential is an HIV reporting process that both ensures confidentiality and is in the best interests of public health.

Accordingly, the report recommends:

- **additional seroprevalence studies**, especially among populations not yet surveyed;
- a policy of **HIV reporting with identifers**, under the strictest level of confidentiality;
- the encouragement of **confidential testing for HIV**, along with the preservation of the anonymity option;
- the amassing of data to support an appeal to the CDC to **revise the present case definition of AIDS**; and
- the allocation of additional state funds for **HIV/AIDS research**.

II. Slowing the Spread of HIV/AIDS

In the absence of a vaccine, education remains our best weapon for preventing the spread of HIV infection. However, although public awareness campaigns have been successful in reducing the rate of infection in some at-risk populations, they have been less effective in others--including New Jersey's large number of IVDUs. We must therefore renew our education efforts, making sure that it is linguistically and culturally sensitive, carefully targeted to specific audiences and based, to the greatest extent possible, in the community. The report recommends:

- the implementation of a **targeted prevention and education campaign**, designed for both the general public and for certain special populations which are listed in the full report. One component of the campaign will be the establishment of a **People with HIV/AIDS Speakers Bureau**;

- the use of state funds for the **puchase and distribution of condoms**;

- the enhancement of HIV/AIDS education and prevention activities and policies for the workplace; and

- the establishment of an **Office of Women and AIDS** within the Division of AIDS.

III. Delivering HIV/AIDS Care and Treatment Services

With the recent introduction of new drug therapies, aggressive early-intervention care and treatment of HIV infection is now replacing defensive and, too often, only palliative care. New Jersey's Treatment Assessment Program (TAP) was implemented in 1989 to deliver these early-intervention care and treatment services. The program has been successful, but needs to be expanded to meet the increasing demand. Ways must also be found to alleviate the shortage of trained health care personnel willing and able to treat HIV/AIDS patients. Also urgently needed are more effective coordination of both core and support services, and the adaptation of these services for special populations. This will be facilitated by the establishment of regional HIV/AIDS Resource Centers--focal points for an improved community-based case management system.

The report recommends:

- the construction and implementation of a regionally based system of **HIV/AIDS Resource Centers**. These centers, which will rest on community-based case management, will more effectively coordinate the provision of HIV/AIDS services;

- the provision of more accessible **core HIV/AIDS services**, such as community-based case management and early-intervention care and treatment;

- the improved and expanded delivery of **HIV/AIDS support services**, such as home health services, volunteers, and transportation, and their coordination by the resource centers;

- the expansion, where appropriate, of **subacute care facilities** for HIV/AIDS patients;

- the shaping of care and treatment programs to fit the needs of **special populations**; and

- an **HIV/AIDS housing needs assessment**, followed by funding for the diverse types of housing required by people with HIV/AIDS.

IV. Coordinating and Evaluating HIV/AIDS-Related Services

Because the scope of the HIV/AIDS epidemic is so broad, and because its face changes continually, a flexible, comprehensive response must be developed. This necessitates a broad array of programs and activities. It is critical that these programs be well-coordinated and broadly based across the various agencies of both state and local government and the private sector to achieve maximum effect. The best way to ensure this is through a careful examination of all grant requests and an effective evaluation of the results of program activities. Also needed is an ongoing planning body to advise policy makers on matters related to the epidemic.

The report recommends:

- the identification of opportunities for **interagency collaboration** among the departments of New Jersey state government in HIV/AIDS-related programs and activities;

- the **regular evaluation of all HIV/AIDS-related activities**, to ensure that limited resources are directed to effective priority programs; and

- the formalization of a permanent **AIDS Advisory Council**.

FINANCING HIV/AIDS SERVICES

Financing strategies for this epidemic must balance the high cost of HIV/AIDS services against its human cost in pain and suffering. In the light of the state's current fiscal difficulties, such a balancing act will not be easy. Several approaches should be taken concurrently.

These include:

- an assessment by the Division of AIDS Prevention and Control of all HIV/AIDS activities presently supported by state funds, in order to ensure that these funds are wisely allocated;
- the seeking of additional federal and private funding, to be facilitated by the addition of a grant-writing team to division staff;
- efforts to improve cooperation and coordination with other state agencies, the Governor, the State Legislature, and the private sector to avoid duplication and increase efficiency;
- the continued full use of CDC funds to support the present range of division activities;
- the use of state-appropriated FY92 funds to establish three to five HIV/AIDS Resource Centers; and
- the application for over $4 million in federal funds under Title II of the Ryan White CARE Act.

The Department of Health will also work closely with the Medicaid program to improve the present services needed by people with HIV/AIDS. The department will also ask Medicaid to consider funding case management services, the continuation of employment-based health insurance coverage for those eligible under COBRA regulations, and appropriate incentives for nursing homes to admit HIV/AIDS patients.

The department will also explore with the Governor and Treasurer the possibility of using Casino Tax Revenues to support HIV/AIDS activities. This revenue is constitutionally earmarked for programs for the disabled; under current law, persons with HIV/AIDS are considered disabled.

CONCLUSION

The development of this statewide HIV/AIDS plan began 100 days ago, at the behest of Governor Florio. Its submission marks not the end but the beginning of a dynamic and ongoing planning process for HIV/AIDS issues which will be continued by the creation of an AIDS Advisory Council.

At each of four public meetings held in November and December, the people in the front lines of the war on AIDS--and people with HIV/AIDS--implored those participating in the development of this plan to ***make some sense*** of our response to the HIV/AIDS epidemic.

We heard them. The common thread running through this report is the need to develop a coordinated plan to fight AIDS; to draw up a blueprint for action that optimizes and maximizes the resources we are expending to learn more about the epidemic, to arrest its spread, and to care for its stricken.

Times are tough; resources are scare. But the recommendations set forth in this report deserve careful consideration by policymakers--not only because they are the product of much time and concerted effort, but because they are the best answer we can devise to a heartfelt, eloquent cry for help.

INTRODUCTION

INTRODUCTION

GOVERNOR JIM FLORIO, deeply concerned about the HIV/AIDS epidemic in New Jersey, outlined on October 11, 1990 the scope of a ten-point proposal for fighting the epidemic in the state.

> ***"Please stop making AIDS a political disease and treat it as a health crisis."***
>
> *--Carol DeGraw*
> *Paterson Division of Health*
> *Camden Public Meeting*

> ***"Things are going to get worse, we all know that. I mean, I'm not the only one who got married, had kids, had a house and lost the ground underneath me."***
>
> *--Marilyn, PWA*
> *Camden Public Meeting*

In an address in Atlantic City before an audience of some 600 foster parents, the Governor directed Health Commissioner Dr. Frances J. Dunston to prepare a "plan of action against AIDS...which will serve to ***coordinate*** all statewide efforts to fight this terrible disease. "The plan that follows is Commissioner Dunston's -- and New Jersey's --response to Governor Florio's charge. It draws on the input of AIDS "experts," in both public and private sector, as well as people with AIDS and their families, to address the crisis posed by this disease. It sets short- and long-term goals, makes recommendations, and initiates a dynamic process for achieving them. The plan is a blueprint for action intended to take New Jersey forward to the year 2000 as a state organizing to fight AIDS.

Commissioner Dunston's report embraces Governor Florio's ten principles, and is driven by eight overarching themes. They provide a framework for this statewide plan to meet the challenges of the HIV/AIDS epidemic:

- HIV/AIDS illuminates the frailties of New Jersey's health care and social service systems;
- a reliable, structured system must be established to better deliver critical services to those who are HIV-infected or who have AIDS;
- an effective mechanism of evaluation and accountability must be built into this system;

- New Jersey's HIV/AIDS prevention and outreach services must address the distinct needs of special populations which have not been sufficiently addressed in the past;

- greater reliance and emphasis must be placed on community-based HIV/AIDS-related services;

- better, more efficient use must be made of existing public and private resources--but efforts must also be made to increase resources;

- HIV/AIDS is a disease which affects entire families of New Jerseyans and requires services which are more family-focused;

- emphasis must increasingly be placed on ***living*** with HIV/AIDS, rather than dying of it.

WHAT ARE THE CHALLENGES that confront New Jersey as we prepare to implement this plan?

Governor Florio's call for action on all fronts against HIV disease and AIDS come in the face of a threat to human health that is unparalleled in our time, and one that presents the American public health community with its greatest modern-day challenge. By the end of November 1990, the federal Centers for Disease Control (CDC) had recorded more than 150,000 cases of AIDS nationally since the beginning of the epidemic. Nearly 100,000 have died--a figure approximating the number of Americans killed in the Korean and the Vietnam Wars.

The CDC predicts that there may now be as many as one million Americans infected with HIV, and that there will be more than 250,000 cumulative cases of AIDS in the United States by the end of 1992. From where we now stand, we cannot see the end of AIDS.

The HIV/AIDS epidemic has had other consequences of great significance. Perhaps most importantly, it has illuminated the frailty of the American health care system. People with HIV disease and AIDS need not only treatment, but a host of other social and health care services. Their desperate attempts--and frequent failures--to obtain these services have taught us, as perhaps no other threat to public health has, that our national and state health care and social service systems are in deep trouble. ***The plan presented here will attempt to rationalize and make sense of the way we care for those afflicted by AIDS by creating in our state a comprehensive and coordinated system of HIV/AIDS service delivery, including county-based case management and regional HIV/AIDS Resource Centers.*** If this plan proves effective, its success may have much to tell us about what we must do to

provide accessible and affordable health care and related services for ***all*** New Jerseyans.

NO MATTER HOW EFFECTIVE New Jersey's plan is, it must confront an immense challenge, for the HIV/AIDS epidemic has battered the state. In November 1990, New Jersey recorded its 10,000th diagnosed case of AIDS. This places New Jersey fifth among states in cases diagnosed to date. It is further believed that the number of HIV-infected New Jerseyans is in the neighborhood of 40,000 or more. This is a terrible toll, rendered even worse by the way that the disease has struck certain groups with particular ferocity. Much more than in most other states, HIV infection and AIDS in New Jersey have hit minorities hardest. Two-thirds of the state's people with AIDS are Blacks and Hispanics. This places yet another burden on a population that is already coping with myriad other socioe-conomic problems and societal ills.

The tragic nexus between intravenous drug use and AIDS makes New Jersey's HIV/AIDS epidemic even more difficult to confront. Eighteen percent of AIDS cases in the U.S. are among intravenous drug users (IVDUs); in New Jersey the figure is ***55 percent***--and this does not include the sexual partners of these drug users, or their offspring, whom they may have infected.

Another problem noted by Governor Florio is that HIV/AIDS is increasingly becoming a ***family disease***. The 1989 report of the New Jersey Pediatric AIDS Advisory Committee, "Generations in Jeopardy," reminds us that "in New Jersey, the HIV epidemic wears the face of a woman or an infant more often than it does elsewhere in the country." The fastest-growing category of people with AIDS in the state is women of childbearing age, and New Jersey ranks third among the states in the number of infants and children with AIDS, with 10 percent of the nation's total.

Finally, New Jersey's health care and social service delivery systems are ailing. Their fragmentation and unresponsiveness, combined with the lack of means of many people with HIV/AIDS, have resulted in poor access to care for far too many New Jerseyans who desperately need it.

The situation, both nationally and in New Jersey, is worsening. Some observers have noted that HIV-infection rates have declined somewhat in certain at-risk groups, and have concluded that the worst of the epidemic is behind us. Nothing could be further from the truth. We have seen only the tip of the AIDS iceberg. The long latency (incubation) period of HIV--as many as ten years, or more--ensures that an increasing number of AIDS cases will be reported for many years ***after*** the incidence of infection has stabilized, or even begun to decline. According to Dr. June E. Osborn, chairperson of the National Commission on AIDS, "Numerically, the HIV epidemic in the decade

of the 1990s will be far worse that what we have seen so far, and it will touch us all."

In New Jersey, as elsewhere, a realization of the universality of AIDS, and of the threat it poses, was in some respects slow in coming, perhaps because AIDS primarily struck certain well-defined populations outside the mainstream of American society. This situation was further exacerbated in the early 1980s when the federal government slashed domestic spending, including that related to health care. The early response of most state governments was slow and disjointed.

In the absence of an energetic response from government, dedicated individuals and community-based organizations tried to fill the many gaps in the health care and service delivery system. Their efforts have been admirable, even inspiring. Even combined with increased activity by the public sector in more recent years, however, they have not been sufficient to stem the tide. Early in 1990, members of the National Commission on AIDS visited some of the cities--including Jersey City--which have been hardest hit by the epidemic. Upon their return, chairperson June Osborn told a Congressional committee that

> the anguish we witnessed--the destitution, the unthinkable daily jeopardy of persons who lack homes and food and health care, whose families have been decimated by poverty and chemical dependency, and whose lives are now under threat from HIV and AIDS--all those abstract components of tragedy took human shape in the narratives of personal experience, and were made all the more real to us by the poignant pleas for understanding by the homeless people we talked with. The brave advocates and outreach workers who facilitated our meetings left me in awe of the courage they display just in returning, day after day, to a battle when they have no ammunition and, indeed, no battlefield on which to stand.

NEVERTHELESS, THE RECORD REFLECTS that New Jersey has done much since the mid-1980s in the areas of education and prevention, epidemiology, counseling, testing and partner notification, case management, and the development of model care and treatment centers. Some examples of New Jersey's initiatives and programs include:

- Targeted education and prevention programs tailored to high-risk populations and aimed at altering risky behavior; for example, the multi-media "Bands to Beat AIDS" campaign aimed at adolescents, and the Coupon Program, which met with much success in bringing drug users into treatment;

- New Jersey's counseling and testing network, which extends to family planning clinics, prenatal care clinics, and drug treatment centers, as well as free-standing centers, and in which more than 30,000 individuals were tested in 1989 and an additional 32,000 were seen in the first nine months of 1990;

- The state's case management system, which began with a grant from the Robert Wood Johnson Foundation that organized case management in the two counties, Essex and Hudson, having the highest number of reported AIDS cases in the state;

- New Jersey's model care and treatment centers, such as the Children's Hospital AIDS Program (CHAP) in Newark, St. Clare's Home for Children in Elizabeth, and the Treatment Assessment Program (TAP) sites, which provide comprehensive HIV and AIDS services--including early intervention--at five hospital-based clinics statewide; and

- The Department of Health's Division of AIDS Prevention and Control, created in 1988 to coordinate all planning for the struggle against this virulent epidemic and designated by the Governor to be the lead agency for the development of this State Plan for AIDS.

New Jersey's response to AIDS has been significant. Several New Jersey programs have become national models. The Treatment Assessment Program places the emphasis on ***living*** with AIDS rather than dying of it, and this plan will reaffirm this critical change in the way we look at AIDS. Much good work has been done by local and state public health officials, by care providers at every level, and by community-based organizations and volunteers.

BUT AS WE NEAR THE END of the first decade of the "Age of AIDS," we must nevertheless conclude that in New Jersey, as elsewhere, much more needs to be done. Testimony presented at each of the four public meetings held in conjunction with the development of this plan has convincingly reinforced this point. Witness after witness--care providers, employees and volunteers in community-based organizations, and people with HIV disease and AIDS--testified to the inadequacy of the present system to cope with the material and emotional consequences of this epidemic. The testimony made crystal-clear that in the fight against AIDS there is not enough of anything: not enough money; not enough care facilities and competent caregivers; not enough transportation to what facilities there are; not enough housing; not enough drugs of the right kind (and too many of the wrong); and not enough compassion and understanding. "We are overwhelmed by this

disease," summed up Robert Maher, president and chief executive officer of St. Michael's Hospital in Newark.

We are falling short in many areas--and in none more fundamentally than in the area of ***service coordination***. This element is the most critical component of our effort, if we are to fight this epidemic successfully. The problem is not peculiar to New Jersey; it is a national concern. In its second report to the President, the National Commission on AIDS stated:

> A lack of clear definition of government roles at all levels has hampered our ability to organize health care services, to recruit and train human services personnel, to provide housing for the sick, to provide effective AIDS education and prevention programs, to provide coordinated, comprehensive substance abuse treatment and prevention and to develop sufficient monies to finance all of these efforts. . .There is no question that there have been creative and often heroic efforts at every level of government to address the HIV epidemic, ***but coordination of these efforts is the missing link to an effective national strategy***.

In New Jersey, as elsewhere, this lack of coordination has been crippling the AIDS effort. Any person with AIDS needs both medical and non-medical services, but the great majority of New Jersey's people with HIV disease and AIDS are also poor, without adequate housing, and often addicted to drugs. They require a particularly broad array of support systems and services outside those traditionally defined as "medical." They need not only a continuum of care and support, but also creative case management to help them make their way through the bureaucratic health and social services maze.

Despite the best efforts of public health workers and social services providers, many of New Jersey's people with HIV disease and AIDS are not receiving enough of that kind of help. One after another, people with AIDS spoke out at the hearings, many for the first time, about what it is like to live with AIDS in New Jersey. One after another they described a system that is not working for them; an uncoordinated system that shuttles them from site to site; a system that never seems to treat them as a "whole person." Barbara Ford, AIDS Coordinator for Newark, perhaps said it best: "The system has been set up for these people to fail, and then you ask us why they are failing. They are failing because the system is a failure."

The system is ***not*** failing because of a lack of talented, dedicated people across the state--in every county of the state--who are doing what they can to stem the tide. They are out there. It is failing because we are not using the considerable resources we have--material as well as human--wisely and well enough. Our failure is, or has been until now, a ***failure to plan***. That is why Governor Florio has asked Commissioner Dunston for an action plan to fight AIDS--to "win this fight, no matter how long it takes." That is why the plan that follows calls for a better-structured, comprehensive system for delivering HIV/AIDS-related services to all New Jerseyans who need them. That is why this plan, periodically modified to fit changing circumstances, will be the one indispensable tool for fighting AIDS in New Jersey as we move to the year 2000.

IN HIS OCTOBER 1990 ADDRESS, Governor Florio called AIDS a "community disease," and, from the beginning of this terrible epidemic, most New Jerseyans have responded in the spirit of community. Despite differences of opinion, that same spirit has imbued those who were convened by Dr. Dunston to work on this first state plan for AIDS in New Jersey. During this process, they confronted an array of social, moral and ethical, legal, psychological, economic, and public health questions. For many of them, there are no easy answers:

- How can a streamlined, comprehensive and cost-effective HIV/AIDS care and service delivery system be crafted from a health care system that is fragmented, sometimes irrational, and ruinously expensive?

- What kind of public education and awareness programs can be created, given the knowledge that years of such programs have left many Americans insufficiently informed about, and in many cases irrationally fearful of, HIV/AIDS?

- How can a counseling and testing system be devised which, at the same time, ensures confidentiality and facilitates early treatment intervention for the HIV-infected?

- What policies can be developed to ensure that there are an adequate number of health care professionals to treat HIV/AIDS patients? Is there an ethical obligation to treat an infectious, fatal disease?

- In what areas can, and should, the State Legislature be involved in establishing policy related to HIV/AIDS?

- How can the private sector be encouraged to work hand-in-glove with government in a joint effort to confront the HIV/AIDS epidemic?

- What can be done to eliminate discrimination against the HIV-infected and people with AIDS?

The questions have been addressed; recommendations made; and the dynamic process of working to realize them is beginning. It behooves all of us to continue to work with the same spirit of community with which we began last October. The stakes are very high. In 1988, Harvey V. Fineberg, dean of the School of Public Health at Harvard, wrote:

> Our world has been made a different place by the human immunodeficiency virus. More profoundly, our society is being shaped by our response to the epidemic. . . .Will AIDS be perceived as a universal threat to all humanity, or will it be regarded as a problem of the underclass, the poor and uneducated, and the minorities? Will AIDS heighten the tension between moralistic and pragmatic approaches to behavior and health, or can solutions be found that are both effective and morally acceptable? Will AIDS evoke the selfless dedication of physicians, nurses and other health professionals, or will caregivers shun AIDS patients and seek other ways to practice their craft? How we choose to answer these questions, and the society we thus shape, is up to us.

New Jersey will make considerable progress toward finding answers to these questions with the implementation of the HIV/AIDS plan that follows.

METHODOLOGY

METHODOLOGY

THE HIV/AIDS EPIDEMIC has called forth energetic responses from much of the New Jersey community: public health professionals, hospitals, long-term care facilities and other care providers, community-based organizations, advocacy groups, and concerned individuals.

For this reason, and because the AIDS crisis presents us with a uniquely complex set of medical, social, ethical, financial, legal, administrative, and legislative challenges, both Governor Florio and Commissioner Dunston realized that the development of a state plan to address these issues and concerns would require the participation of the broadest possible range of groups and individuals with expertise in all of these areas. "We must be confident that we have the courage, the compassion, and the know-how to win this fight," the Governor said in his October AIDS address. "Our entire state community must join the fight, because AIDS is a community disease."

In that spirit, and to that end, the Division of AIDS Prevention and Control of the Department of Health began immediately to assemble an AIDS "brain trust"--a wide array of the best minds in the state among those knowledgeable and concerned about AIDS. At the outset a decision was made to divide this group into three working committees:

- the ***Departments of the State of New Jersey Advisory Committee,*** composed of the commissioners of those state departments that conduct HIV/AIDS-related activities.

- the ***Intradepartmental Advisory Committee,*** composed of the assistant commissioners who head the several divisions within the Department of Health; and

- the ***Community Advisory Committee***, composed of more than 40 individuals--legislators, health officers, care providers, members of community-based organizations and AIDS advocacy groups, and concerned individuals--including people with HIV disease and AIDS. (A complete list of the members of this committee can be found in the Appendix.)

Additionally, four public meetings were held in Newark, Trenton, Camden and New Brunswick. Many individuals, representative of every facet of the AIDS effort, as well as people with AIDS, testified before members of the

Community Advisory Committee, the assistant commissioner of the Division of AIDS, Douglas Morgan, and Commissioner Dunston. At the beginning of each hearing, the Commissioner stressed that what those testifying had to say was of the utmost importance--the "most critical element"--in the plan-development process. "I want you to know that we are listening very carefully to what you have to say," the Commissioner told those gathered for the Camden hearing. "You can be sure that many of your ideas and thoughts will be incorporated in the State AIDS Plan."

The three working committees met separately over several weeks, and each developed its set of recommendations for this plan. The Departments of the State of New Jersey Committee presented the current HIV- and AIDS-related activities in each department of state government, with an eye toward developing a better-coordinated response to the epidemic. The Intradepartmental Committee analyzed the Department of Health's current efforts, by division, to determine how current resources might be more efficiently and effectively coordinated.

The Community Advisory Committee--by far the largest of the three, and representing the widest range of viewpoints--was divided into three sub-groups covering epidemiological, prevention and education issues; care and treatment issues; and legislative issues. Each sub-group met separately on several occasions, formulated recommendations, and presented them to the full committee. Such factors as issue background, means of implementation, and financial impact were consistently considered.

As the process progressed, each committee was provided with minutes of the meetings of the other two, as well as with verbatim transcripts and synopses of the public hearings. This remarkably open process provided the kind of cross-fertilization of ideas so necessary when considering such a complex issue.

The three committees then met in plenary sessions to review all the recommendations and to suggest revisions. Staff of the Division of AIDS, in consultation with the Commissioner of Health, then drafted the plan for submission to Governor Florio on January 31, 1991.

PROFILE OF THE HIV/AIDS EPIDEMIC IN NEW JERSEY

A PROFILE OF THE HIV/AIDS EPIDEMIC IN NEW JERSEY

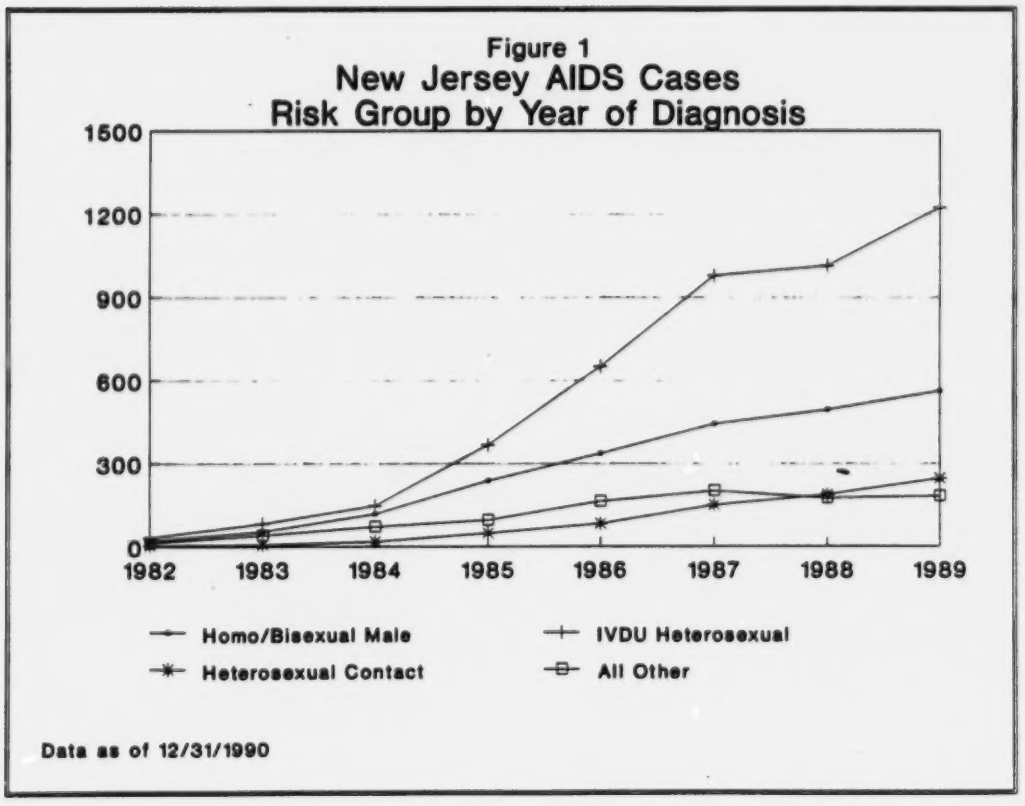
HIV/AIDS in New Jersey

In November 1990, New Jersey registered its 10,000th reported case of AIDS. This unfortunate milestone represents only a tremor compared to the impending quake. It is estimated that between 30,000 and 50,000 New Jerseyans are presently infected with the HIV virus (including those with full-blown AIDS). Although the rate of increase has slowed slightly, it is clear that the absolute number of people with AIDS (PWA's) will continue to grow.

What Makes New Jersey Different?

New Jersey ranks fifth nationally in the cumulative number of cases of AIDS reported since June 1981. The AIDS epidemic in New Jersey, however, has developed in a markedly different manner than in other states. In New Jersey, gay men do not account for the majority of diagnosed AIDS cases; rather, HIV/AIDS has occurred predominantly as a result of intravenous drug use. All ages, sexes, racial/ethnic groups and lifestyles are significantly represented among New Jersey's AIDS cases (Figure 1).

Figure 1



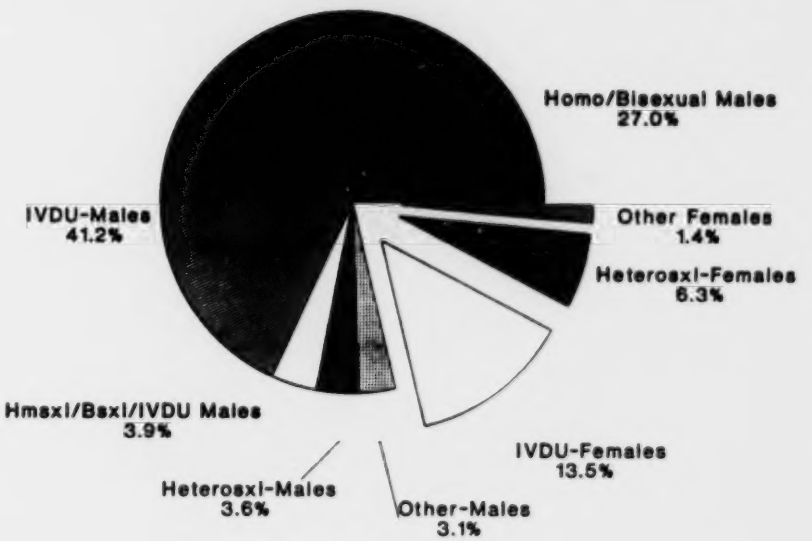
Populations At Risk

- **Intravenous Drug Users**

  Approximately 55 percent of all HIV/AIDS cases among adults diagnosed in New Jersey have occurred as a direct result of intravenous drug use. Of reported AIDS cases in the state, 41 percent are heterosexual men who inject drugs intravenously, as compared to 17 percent nationally. Thirteen percent of the AIDS cases in the state are female IVDUs; this is more than double the national figure of 5 percent. New Jersey's primary reservoir of HIV-infected individuals consists of poor, inner-city present or former IVDUs and their families (Figure 2).

Figure 2

New Jersey Cumulative AIDS Cases
Adult/Adolescent Transmission Category

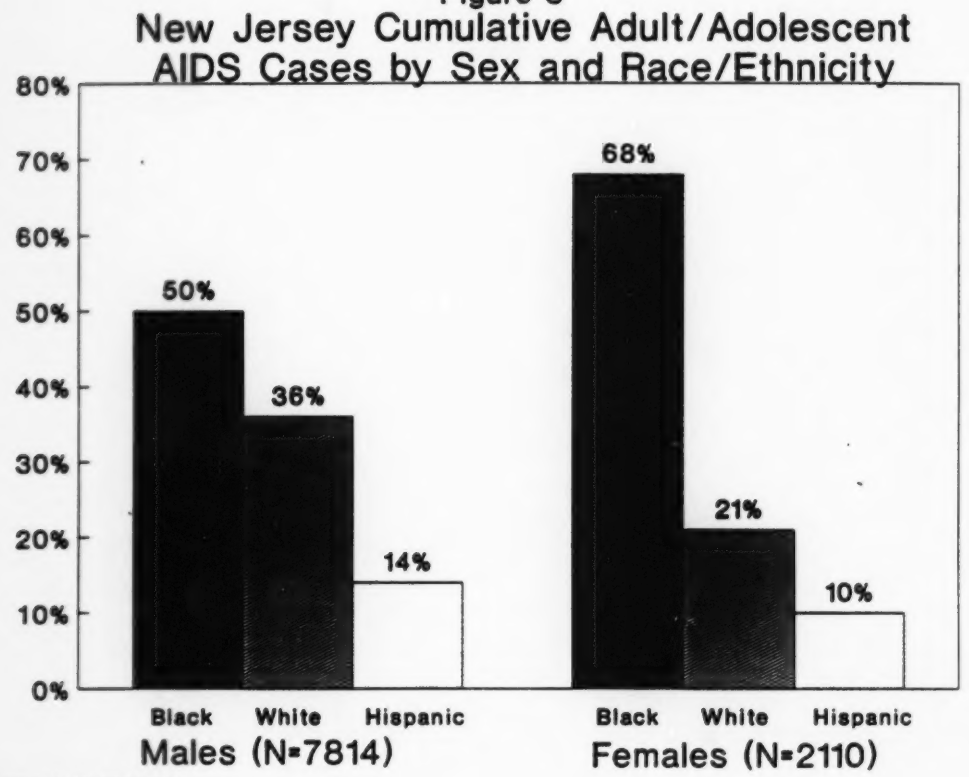


Data As Of 12/31/90 (N=9924)

- **Women**

HIV/AIDS strikes New Jersey's women--especially minority women--more severely than almost anywhere else in the nation. From December 1989 through November 1990, women accounted for 23 percent of all reported cases among adults in New Jersey, compared to 11 percent in the nation as a whole.

Figure 3

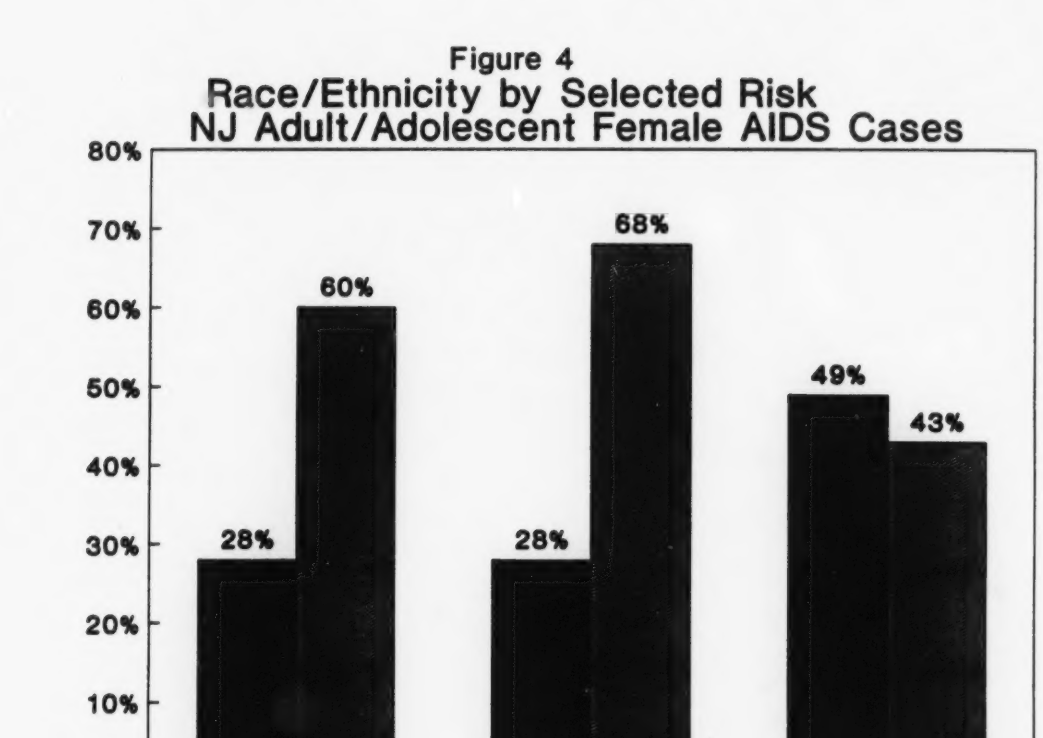


Data as of 12/31/90

Black and Hispanic women account for 78 percent of all New Jersey women diagnosed with AIDS--higher than the national figure of 72 percent (Figure 3). Ninety percent of the state's AIDS cases in women have occurred among those of childbearing age (15-44), and 25 percent were 20-29 years of age at diagnosis. In 1988 AIDS/HIV was the leading cause of death among Black women of childbearing age (15-44) in New Jersey and the fifth-leading cause of death among white women of that age group.

Almost two-thirds of all New Jersey women with AIDS were IVDUs and another 30 percent had had heterosexual contact with a man at risk of infection, or known to be infected, with HIV. The proportions for Black women were 68 percent IVDU and 28 percent heterosexual contact cases, and for white women 60 percent IVDU and 28 percent heterosexual (Figure 4). On the other hand, only 43 percent of Hispanic women were IVDUs and 49 percent were heterosexual contact cases. Over one-half of all the women infected through transfusion were white. This group consists mainly of women over 60 years of age.

Figure 4



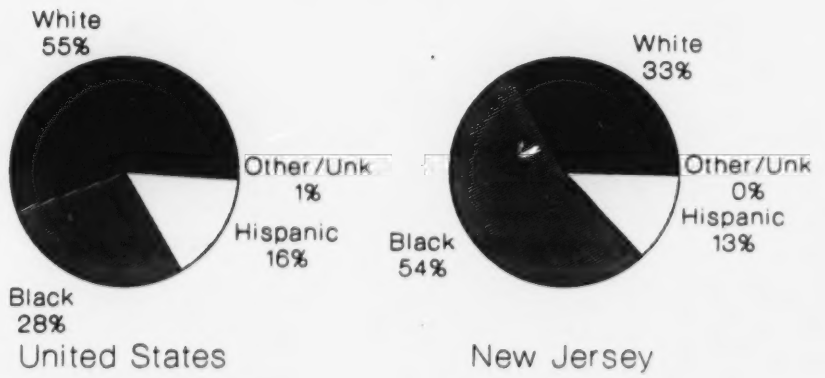
Data As Of 12/31/90

- **Minorities**

The racial/ethnic disparity is far greater in the state than it is nationally. Blacks and Hispanics in New Jersey account for about 67 percent of its AIDS cases, while constituting only about 19 percent of its population; for the United States as a whole, the figures are 44 percent and 18 percent, respectively (Figure 5). Blacks and Hispanics also account for 80 percent of New Jersey's pediatric cases (Figure 6) and 81 percent of the cases infected by heterosexual contact, about half of whom are minority female partners of intravenous drug-using men. The trends are also clear: since the onset of the epidemic, the proportion of cases that are Black and Hispanic has steadily increased. Blacks and Hispanics are overrepresented in every HIV risk group except hemophiliacs. These are also the communities whose residents who are more likely to have children born into poverty, who drop out of school, who are unemployed and uninsured for health services. AIDS, then, is increasingly becoming a disease not only of the family, but of the economically and socially disadvantaged.

Figure 5

Cumulative Adult/Adolescent AIDS Cases by Race/Ethnicity

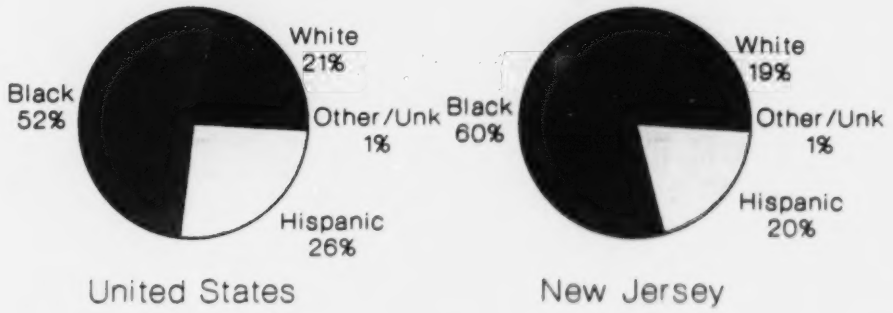


U.S. Data As Of 11/30/90 (N=154,791)

N.J. Data As Of 12/31/90 (N=9,924)

Figure 6

Cumulative Pediatric AIDS Cases by Race/Ethnicity



U.S. Data As Of 11/30/90 (N=2,734)

N.J. Data As Of 12/31/90 (N=277)

- **Children**

New Jersey ranks third nationally in total reported pediatric AIDS cases, with 10 percent of all reported cases nationally. Most children with AIDS have acquired the disease perinatally. Over 90 percent of these children have one or both parents who are infected with the AIDS virus or are at high risk for contracting AIDS. In most cases the parents of children with AIDS, or their sexual partners, are IVDUs. It has been clear for a long time that the problems of drug abuse and pediatric AIDS are inextricably linked.

The majority of pediatric cases in New Jersey are found in the northeastern counties of the state. A seroprevalence study conducted on all newborns found that the average rate for New Jersey is 0.50 HIV-positive newborns per 100 births. The three counties with the highest newborn seroprevalence rates were Essex, Hudson and Passaic. This translates to the expectation that ***six hundred babies will be born to HIV-positive mothers in New Jersey this year***.

Where is the Epidemic Headed?

Absent a cure or AIDS vaccine, the incidence of HIV/AIDS will continue to rise over the next few years, and into the foreseeable future. Although the rate of increase has slowed for some risk groups, there is convincing evidence that there remain tens of thousands of New Jerseyans who are infected with HIV, but who have not yet been diagnosed. As the clinical definition of AIDS is broadened to reflect the actual experience and diagnoses of people with AIDS, practitioners will, in turn, expand their efforts to offer testing to a broader array of the population. There can be no doubt that the incidence of HIV/AIDS cases will increase.

Although the incidence of HIV infection among heterosexuals who are not IVDUs remains small in absolute terms, their numbers are increasing at a rapid rate.

The Geographic Distribution of AIDS in New Jersey

The HIV/AIDS virus has been reported in every county of the state. However, due to the concentration of IVDUs in the urban, northeastern part of the state, particularly in Essex and Hudson Counties, these areas report a disproportionate number of AIDS cases. This is due, in large measure, to the concentration of reported cases in Newark, East Orange, Jersey City, Paterson and Elizabeth.

Forecasting HIV and AIDS

No other situation has presented public health policymakers with as wide a range of social, ethical and medical issues as that of AIDS/HIV infection. Increasing mortality and morbidity due to this disease and uncertainty about how to treat it have generated discussion concerning the development of strategies to address the various issues presented by the epidemic.

The basis for all estimates and projections of AIDS in this report is the AIDS surveillance data collected from health care providers throughout the state. This information is collected for the purpose of tracking the epidemic and providing information for policymakers and planners. The methods used to calculate the future incidence of AIDS have been based on an empirical extrapolation model of the surveillance data (by projecting future numbers from known current ones for certain populations). The overall estimate of AIDS case in New Jersey through 1992 is 17,500. This is based on reported incidence, adjusted for reporting delays, but with no adjustment for underreporting. National estimates of an 85 percent level of case reporting (that is, 15 percent underreporting) would suggest multiplying all projections and estimates by 1.18.

Table 1 presents the current and projected short-term future scope of AIDS in New Jersey. Shown there are the year-by-year data, both unadjusted and adjusted, through 1989, and projections for 1990 to 1992. The annual and cumulative incidence projections for the latter three years have been rounded.

TABLE 1
AIDS PROJECTIONS FOR NEW JERSEY

Year of Diagnosis	Unadjusted As of 9/90	Adjusted/ Projected	Cumulative Cases	Projection Range Min.	Max.
Pre - 1984	281	282	282	NA	NA
1984	353	352	634	NA	NA
1985	759	759	1,393	NA	NA
1986	1,233	1,244	2,637	NA	NA
1987	1,771	1,800	4,437	NA	NA
1988	1,869	1,982	6,419	NA	NA
1989	2,211	2,445	8,864	NA	NA
1990	1,724	2,600	11,500	2,100	3,050
1991	NA	2,800	14,300	2,300	3,350
1992	NA	3,100	17,400	2,500	3,650
TOTAL	10,201	17,500	—	15,800	19,000

Note: Annual and cumulative incidence for 1990-1992 rounded to the nearest hundred. Adjusted for report delay, not for underreporting.

Methods

Estimating the actual size of the HIV-infected population is a puzzling and frustrating endeavor, but it is at the heart of many policy and planning decisions. Numerous research projects have been undertaken to determine the extent of HIV prevalence. Various clinic-based seroprevalence studies conducted in cooperation with the Centers for Disease Control (CDC) show that the northeastern section of the country--especially New York City and New Jersey--has a higher rate of HIV infection than most other parts of the nation.

Using three different methods in which we extrapolate from known data, we can calculate that at the end of 1990 between 30,000 and 50,000 New Jerseyans will be infected with HIV (this includes AIDS cases). For planning purposes, a population of 40,000 people infected with HIV is offered because it lies approximately midway between the two best estimates we have (34,000 - 43,000). Although subject to change based on additional information, this number is consistent with current and projected AIDS reports for the next two years.

TABLE 2
HIV INFECTION ESTIMATES FOR NEW JERSEY

- **Current Estimates**

  Range: 30,000 - 50,000
  Point Estimate: 40,000

- **Estimated CD4 Count Distribution**

CD4 Count	Estimate Using Data From: Army Personnel		TAP Clients	
> 500	16,800	(42%)	7,200	(18%)
200-500	16,400	(41%)	18,400	(46%)
< 200	6,800	(17%)	14,400	(36%)
TOTAL	40,000	(100%)	40,000	(100%)

Implications

The importance of early intervention with prophylactic therapies has been emphasized since mid-1989. For the most part, immune cell levels (CD4 counts) are an integral component of the diagnostic procedure. Individuals with CD4 counts of 500 or above have strong immune systems and are less likely to become ill due to opportunistic infections. Persons with CD4 counts below 200 have been shown to be at high risk for becoming seriously ill and requiring hospitalization. Therefore, knowing the proportions of CD4 counts in any HIV-infected population will allow planning for their medical and social needs. In Table 2, two populations (U.S. Army Survey; New Jersey State TAP Clients) and their CD4 counts are given for comparison. The New Jersey TAP population, based on the larger proportion of people with CD4 counts below 200, is probably sicker and will need more health services. The implications of this data for the health care system need thorough examination.

TABLE 3
HIV INFECTION AND AIDS RATES † FOR NEW JERSEY COUNTY

	1990 HIV Estimates			1989 AIDS Cases
County	Percent of HIV + *	Number of HIV +	Rate per 100,000	Rate per 100,000
Atlantic	2.81	1,124	527.2	45.0
Bergen	4.66	1,864	224.7	11.3
Burlington	1.45	580	145.9	9.3
Camden	2.55	1,020	203.1	14.7
Capet May	0.36	144	150.0	12.5
Cumberland	0.43	172	124.3	8.7
Essex	33.15	13,260	1,580.6	84.9
Gloucester	0.85	340	155.2	10.0
Hudson	15.25	6,100	1,125.0	51.5
Hunterdon	0.21	84	83.7	2.0
Mercer	2.07	828	250.2	15.1
Middlesex	5.76	2,304	353.5	20.9
Monmouth	4.62	1,848	330.7	22.4
Morris	2.21	884	210.1	9.3
Ocean	2.05	820	199.7	14.9
Passaic	7.45	2,980	643.9	34.1
Salem	0.24	96	144.6	6.0
Somerset	1.36	544	240.4	10.2
Sussex	0.22	88	69.5	4.7
Union	7.37	2,948	589.7	28.2
Warren	0.10	40	45.1	3.4
Prisoners and County Unknown	4.83	1,932		
TOTAL	100.00	40,000		

† Rate per 100,000 population
* Percentages derived from cumulative AIDS cases by county from 1987-1989.

Note: All estimates of numbers of HIV infected rounded to the nearest 100; column may not add to total. AIDS data as of 9/30/90. Census data provisional estimates for 1988.

Table 3 shows the estimated distribution of HIV-infected cases across the counties of New Jersey. The data show that nine of New Jersey's 21 counties have at least 1,000 HIV-infected individuals, and that over half of these have over 2,000 individual cases of HIV infection. Table 4 shows the estimated distribution of HIV-infected cases in the 15 cities with the largest number of currently reported AIDS cases. One-third of these have over 1,000 HIV-positive cases themselves.

TABLE 4
HIV INFECTION AND AIDS RATES † FOR SELECTED NEW JERSEY CITIES

	1990 HIV Estimates			1989 AIDS Cases
County	Percent of HIV + *	Number of HIV +	Rate per 100,000	Rate per 100,000
Atlantic City	1.76	700	1,999.2	191.4
Camden	1.17	500	610.5	36.6
East Orange	5.30	2,100	2,726.4	142.8
Elizabeth	2.95	1,200	1,141.7	59.9
Hoboken	1.00	400	956.2	43.0
Irvington	2.29	900	1,463.3	63.4
Jersey City	10.09	4,000	1,840.1	86.9
New Brunswick	1.33	500	1,267.1	98.8
Newark	21.61	8,600	2,742.0	153.4
Orange	1.26	500	1,595.4	89.3
Passaic	1.35	500	938.8	41.3
Paterson	5.16	2,100	1,513.1	79.3
Plainfield	1.60	600	1,333.9	73.4
Trenton	1.48	600	659.4	35.2
Union City	1.07	400	748.1	31.8
TOTAL	59.43	23,800	1,717.6	92.2

† Rate per 100,000 population
* Percentages derived from cumulative AIDS cases from 1987-1989.

Note: All estimates of numbers of HIV infected are rounded to the nearest 100; column may not add to total. AIDS data as of 9/30/90. Census data provisional estimates for 1988.

The number of AIDS cases is expected to continue rising over the next two years. Although currently projected numbers are lower than some projections made in the past, they still indicate a growing epidemic affecting all groups in all parts of the state.

NEW JERSEY'S RESPONSE TO THE HIV/AIDS EPIDEMIC

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NEW JERSEY'S RESPONSE TO THE HIV/AIDS EPIDEMIC

IN JUNE 1981, THE CDC published the first of many reports about an outbreak of opportunistic infections. The reports linked the infection to homosexual males and the media started to refer to it as GRIDS (Gay Related Immunodeficiency Syndrome). It was over a year before it became clear that the outbreak was being caused by a single agent, as yet unknown, and that it was transmitted through sexual contact and exchange of blood. The name of the group of problems caused by the agent became AIDS--Acquired Immunodeficiency Syndrome.

The HIV outbreak came at a time when efforts in health care in the United States centered on chronic disease and health care cost containment. State departments of health, rate-setting commissions, insurance carriers, and business leaders had become heavily involved in managing health care, and cost-containing mechanisms such as Diagnosis Related Groups (DRGs), average rates per case, managed care, utilization review, and pre-authorization were in place throughout the country. Health care financing began to mandate when, where, who and how long people would be treated. Against this background, the country was unprepared for the HIV epidemic--an epidemic caused by an unknown organism that affected young people and progressed with rapidity from diagnosis to death. Many health officials believed that AIDS would be controlled by the conventional techniques of responding to epidemic disease.

Dr. Ronald Altman, then assistant commissioner of the Department of Health's Division of Epidemiology, and his staff collected data on patients who appeared to have the syndrome in the early 1980s. After two years had passed, and the first 50 or so reports had been collected, he noticed that a pattern had begun to emerge: half of the patients were heroin addicts, who were identified after death. Drug addiction was easy to confirm, because of the needle tracks. But the main emphasis, in keeping with reports from the rest of the country, continued to be on the issue of male homosexuality. Since New Jersey's experience could not be confirmed, it remained an enigma.

In 1982, the emphasis on male homosexuality continued, even though the first cases of female sexual partners, then male heterosexual partners, and finally infants, were identified.

Since infants could not be accused of addiction or adult sexual behavior, the very existence of AIDS among them was questioned. In May 1983, Dr. Jim Oleske, a pediatrician and researcher in Newark, reported the first eight cases of pediatric AIDS in a medical journal. His work was seriously challenged, and it took years for others in the medical research community to respond to his early recognition of pediatric AIDS.

In 1984, the causative agent of the epidemic was identified as a retrovirus, and named the Human Immunodeficiency Virus (HIV). Early that same year, the Department of Health started to transfer its scant knowledge about the epidemic to drug treatment practitioners. In general, the information compared HIV to the Hepatitis B virus and, since the viruses appeared to be passed by the same routes, described some prevention strategies. Potentially explosive topics -- instructing addicts on how to clean hypodermic sets, use bleach, and reduce the risk of infection through sexual practice -- were discussed and eventually these messages were included in prevention efforts. "As with most public bureaucracies, a great deal of time was spent in discussion, and in attempts to balance this urgent epidemic situation with a sense of order," note Richard J. Russo, acting deputy commissioner of the Department of Health in an address last Novemer at the second annual National AIDS Demonstration Research National Meeting.

In 1984, in response to increasing recognition that the HIV epidemic was unusual, the AIDS Assistance Act (New Jersey Statutes 26:5C-1 et seq) was enacted, with a small appropriation. It required that the Health Commissioner establish programs targeted at AIDS education, testing and counseling, and treatment.

EMERGENCE OF PRIVATE INITIATIVES

During this period, in New Jersey as well as across the country, community-based organizations were forming to respond to the HIV epidemic. One of the first in New Jersey was the Hyacinth Foundation, which was founded in August 1985 by Dr. Margaret Nichols. Hyacinth provides buddies, support groups, education, legal assistance, transportation, etc. to HIV-infected persons and their families. Hyacinth was one of the first groups to act as a "gadfly" to push the Department of Health to increase its activities in the area of HIV infection. Since that time, numerous other private initiatives have occurred, either through the addition of HIV/AIDS components to existing programs, or through the formation of new groups to deal specifically with HIV/AIDS.

Among the other private initiatives:

- The Robert Wood Johnson Foundation in 1986 made awards in a $17.2 million program for AIDS service development, focusing on case management. This was the first major financial push to address the epidemic.

- The American Red Cross, the New Jersey Academy of Medicine, the Family Planning Association and Planned Parenthood, the Powhatan-Lenape Nation, and the New Jersey Lesbians and Gay Coalition all added HIV/AIDS-education components to their programs.

- The New Jersey Hospital Association's Committee on AIDS of the Council on Planning developed legislation and a comprehensive, coordinated service model.

- The Center for Home Health Development of the Home Health Agency Assembly of New Jersey initiated education efforts for home health care providers.

- HIV/AIDS task forces were created in every county of the state.

The following groups are representative of those formed to address HIV/AIDS issues:

- New Jersey Buddies, which provides education, buddies, food, PWA financial assistance, referrals, etc., and published "A Resource Guide for Living with AIDS."

- Citizens Commission on AIDS of New York City and Northern New Jersey, privately funded with representation from business, law, publishing and the non-profit sector, which has published a number of reports, including an action agenda.

- Blacks Against AIDS, an Atlantic County support group.

- The AIDS Coalition of Southern New Jersey, which provides buddies, referrals, case management, and support services, and published an AIDS resource directory for Burlington, Camden and Gloucester Counties.

- The North Jersey AIDS Alliance, which published "A Community Resource."

- The Women and AIDS Network, which was formed to ensure adequate resources and services, and to act as an advocate and provide appropriate education.

- The New Jersey Coalition of AIDS Service Providers, a stat-wide alliance of community-based and nongovernmental organizations which provides health care, social and advocacy services for people with AIDS and HIV infection, caregivers and the community at large.

- The AIDS Service Organization/Puerto Rican Association for Human Development, a support and referral group.

- Both the AIDS Clinical Trials Unit at Robert Wood Johnson University Hospital, New Brunswick, and the Community Research Initiative, Newark, which conduct experimental drug therapy trials.

- New Jersey ACT UP, a advocacy and pressure group, which works to educate, rally public opinion and influence policy.

- The AIDS Interfaith Network, which provides pastoral care, and educates and sensitizes its members to HIV/AIDS issues.

STATE GOVERNMENT RESPONSE: THE DEPARTMENT OF HEALTH

Originally, the Department of Health's AIDS activities were concentrated in the Division of Epidemiology and Disease Control, and were directed mainly toward surveillance of the epidemic, educational activities, and policy issues related to AIDS. As it became more and more apparent that the majority of cases in New Jersey were related to intravenous drug abuse, AIDS activities such as educational outreach through drug treatment clinics and provision of care to AIDS patients through these centers were initiated in the Division of Narcotics and Drug Abuse. As the population of drug abusers with AIDS increased, so did these activities, until two divisions were heavily involved with AIDS--Epidemiology and Disease Control, and Narcotics and Drug Abuse.

In 1985, the late Dr. Jack Rutledge, a physician and attorney, joined the Department of Health as a deputy commissioner. Under his leadership, as well as in response to the "front-line" experience of physicians, community-based groups, and Department of Health staff, the department initiated a more aggressive approach to AIDS in New Jersey. By 1986, most of the department's AIDS activities were combined and placed in the Division of Narcotics and Drug Abuse. A list of other initiatives in chronological order follows:

NEW JERSEY'S RESPONSE TO HIV/AIDS

- 1984 - The National Cancer Institute (NCI) in conjunction with the Department of Health conducted one of the first seroprevalence studies in the U.S. among IVDUs in New Jersey. The rates of HIV infection varied from 48 + % to less than 2%, depending on the site.

- 1985 - Ex-drug addicts hired as AIDS educators for drug abusers
  - Blood bank screening of donated blood implemented

- 1986 - Seven counseling and testing sites opened
  - Toll-free AIDS Hotline established
  - Coupon program for free initial drug detoxification initiated; of some 4,000 coupons distributed, 85% were redeemed
  - AIDS programs combined into the Division of Narcotics and Drug Abuse
  - Funds awarded by HRSA to initiate case management
  - Funds awarded by Robert Wood Johnson Foundation for case management

- 1987 - Three more counseling and testing sites opened
  - St. Clare's Home for Children opened in Elizabeth, the first residential, respite, foster care facility for children with AIDS in the country
  - Drug Distribution Program initiated
  - First a dental clinic opened
  - Mobile vans utilized to provide information, physicals, etc., in Newark and Jersey City
  - Medicaid waiver received to pay for home and community-based services (in cooperation with Department of Human Services). New Jersey is the first state to employ the waiver approach.
  - Funding initiated for county and local health departments to offer counseling and testing, outreach, and/or education

- 1988 - Notification Assistance Program implemented
  - Pediatric services offered at Children's Hospital, Newark
  - The CDC Family of Surveys implemented
  - Wanaque Convalescent Center opened 120 beds for AIDS patients
  - Hospitals received add-on to reimbursement rates for care of AIDS patients and universal precaution implementation
  - Division of AIDS Prevention and Control established

- 1989 - AIDS Diagnosis Related Groups (DRGs) implemented for hospital reimbursement. New Jersey was the second state after New York to utilize AIDS DRGs
  - Treatment Assessment Program (TAP), an early intervention program, implemented. It was one of the first plans in the country to formalize testing, early intervention, and prophylaxis.

- 1990 - Reporting of HIV-positive persons to Department passed
  - HRSA funds awarded for a home health care system
  - Perinatal AIDS project funded; one of the first in the U.S.
  - Ryan White CARE Bill passed; funds designated for New Jersey

The first case of AIDS in New Jersey was diagnosed (retrospectively) in July 1980. By the end of that year, a total of three cases had been diagnosed. In the succeeding years, the number of AIDS cases has mushroomed:

NEW CASES DIAGNOSED

Year	In Year	Cumulative Cases
Pre - 1983	98	98
1983	184	282
1984	353	635
1985	758	1,393
1986	1,231	2,624
1987	1,767	4,391
1988	1,862	6,253
1989	2,204	8,457
1990	2,264	10,201

New Jersey's experience with AIDS among drug abusers, women and children has been verified beyond doubt. As AIDS cases rapidly increased, AIDS activities overshadowed the other necessary drug abuse control measures of the Division of Narcotics and Drug Abuse. Because a need for a specific focus on greatly increased and visible AIDS activities, and for the pursuit of an increasingly important program of substance abuse control, with emphasis on cocaine and alcohol abuse control activities, was perceived, a separate division within the Department of Health was created.

- **DIVISION OF AIDS PREVENTION AND CONTROL**

In September 1988, the Division of AIDS Prevention and Control was created by Executive Order #140. This division is headed by an assistant commissioner and currently is composed of the following units: Care and Treatment; Prevention/Education; Epidemiological Services (which includes Counseling and Testing [CAT], Partner Notification [NAP], and Surveillance); Medical Research; Data Analysis; and Administration (which includes the Office of the Assistant Commissioner), Grant Monitoring and Evaluation, Public Awareness, and Administrative Services. The first four units are service oriented; the last two are support units.

As of December 20, 1990, there were 151 positions in the AIDS Division -- 84 state-funded and 67 federally-funded. There were 51 vacant state positions, frozen in 1989 and abolished in December 1990 during the current budget crisis. The goals of the various units in the division are described below.

- **Care and Treatment**

The mission of Care and Treatment is to develop integrated networks of HIV health services including, but not limited to: early intervention and assessment; and ambulatory, acute and post-hospital care for persons with HIV infection, their families and significant others. Robert Wood Johnson and federal Health Resources and Service Administration (HRSA) funding is integrated with state dollars to fund direct services such as residential beds in drug treatment clinics, medical day care and two HIV dental clinics. Other existing programs include medical support, case management, health planning, direct care/community-based services, mental health, ambulatory care, prophylaxis/primary care and a drug distribution program in cooperation with Medicaid. As part of early intervention, Care and Treatment funded five early intervention TAP centers. The first TAP center was operational in October 1989; all five have been in operation since April 1990. The centers provide early intervention at all stages of HIV infection through CD4 counts, monitoring, case management, AZT therapy, Pneumocystis carinii pneumonia (PCP) prophylaxis, and other needed services.

A listing of the grantees funded by the Care and Treatment Unit is attached (Attachment 1). The FY91 amount budgeted for Care and Treatment as of December 20, 1990, was $12,148,000, of which $300,000 was private funds, $8,176,000 state funds, and $3,672,000 federal funds. A total of $10,262,803 (84% of budget) was distributed in grants. (This amount includes $1,900,000 for the AIDS Drug Distribution Program.)

- **Prevention/Education/Public Awareness**

The focus of the Prevention/Education Unit (which includes the Education and Training Programs) is to reduce the spread of HIV infection through targeted educational programs, and through the education of provider groups to help ensure delivery of needed services for HIV-infected persons. This service unit has primary responsibility for educational material distribution (assisted by the Public Awareness Unit); management of the 24-hour AIDS Hotline; media campaigns; the conduct of knowledge, attitudes and behavior surveys; targeted prevention efforts towards minority populations, gay and bisexual men, IVDUs and sexual partners; and "train the trainer" programs for provider populations in health care and services. The Public Awareness Unit produces and distributes HIV- and AIDS-related literature on behalf of all division services areas.

The FY91 amount budgeted for this unit was $5,426,000, of which $2,253,000 was state funds, and $3,173,000 was federal funds. A total of $3,256,510 (60% of budget) in grant awards was given; a listing of the grantees is included as Attachment 2.

- **Epidemiological Services**

One goal of the Epidemiological Services Unit, through its Counseling and Testing/Notification Assistance Programs (CAT/NAP), is to provide geographic access to counseling and testing and partner notification services statewide to populations at risk for HIV infection. The activities are designed to encourage those at risk to learn their HIV status, and through counseling to identify risk behaviors which can be changed to halt further spread of HIV. Individuals learn how to protect themselves and/or how to prevent infecting others. Free anonymous and confidential testing are offered in the voluntary Counseling and Testing sites, and in other clinic settings (Drug Treatment, Family Planning, TB clinics, etc.), where high-risk individuals go for health care. Partner notification is similar to contact tracing for sexually transmitted diseases, and provides an HIV-positive person with aid in informing sexual and needle-sharing partners.

The FY91 amount budgeted for CAT/NAP is $5,670,000, of which $2,014,000 was state funds, and $3,656,000 was federal funds. A total of $4,911,295 (87% of budget) was awarded in grants; a listing of grantees is included as Attachment 3.

A second goal of Epidemiological Services, through its Surveillance Program, is to investigate and ensure the accurate reporting of AIDS and HIV-related illness by time, place and person. Data collection through Surveillance is used by state and national reporting systems for projections and health care planning. Surveillance maintains a confidential AIDS Registry and will maintain an HIV Registry as New Jersey's new regulations on reporting of HIV infection are implemented.

The total amount budgeted for Surveillance for FY91 was $809,000, of which $287,000 was state funds and $522,000 was federal funds. Surveillance awarded $13,000 in grants (1.6% of budget) which is included within the CAT/NAP list (Attachment 3).

- **Medical Research**

The purpose of the Medical Research Unit is to investigate the nature and extent of HIV infection in the general population, as well as in at-risk groups. The Medical Research Unit is a participant in the five-year federal Family of HIV Seroprevalence Surveys, and is conducting studies in blood donors and transfusion recipients and a number of other seroprevalence studies.

The total FY91 amount budgeted for Medical Research was $1,994,000, of which $401,000 was state funds, and $1,593,000 was federal. The amount awarded in grants was $381,739 (19% of budget); a listing of grantees in included as Attachment 4.

- **Data Analysis**

The Data Analysis Unit is a support unit which analyses all AIDS and HIV-related data for the division. It provides estimates of the number of persons in New Jersey with severe HIV-related illness not meeting the CDC criteria for AIDS, and the number of HIV-infected persons. It also analyzes data collected on medical care and other resources needed by HIV-infected people. This unit is particularly concerned with the confidentiality of the data maintained on HIV-infected persons.

The FY91 amount budgeted for Data Analysis was $776,000, of which $177,000 was state funds and $599,000 federal. No grants are awarded by this unit.

- **Administration**

Administration is composed of the Office of the Assistant Commissioner, Grants Management and Evaluation, Public Awareness and Administrative Services. The Office of the Assistant Commissioner coordinates and organizes the work of the division. Grants Management and Evaluation ensures that the terms and conditions of HIV/AIDS-related grants are met. Public Awareness produces and distributes HIV and AIDS-related literature on behalf of all service areas in the division. Administrative Services provides administrative support--personnel, financial and supply matters--to the division. The total FY91 amount budgeted for Administration was $1,138,000, all state funds. This is 4 percent of the division budget.

As of December 20, 1990, the total amount budgeted for FY91 for the Division of AIDS Prevention and Control was $27,961,000. A summary of the budget is included as Appendix VII.

As of January 1991, the Division of AIDS has been reorganized. Public Awareness has moved into the Prevention Unit. The Data Analysis, Medical Research and Surveillance Units have been integrated into Epidemiologic Services. The Counseling and Testing/Notification Assistance Programs (CAT/NAP) are now a separate unit. Some adjustments in the allocation of dollars within the division will occur as a result of this reorganization.

ATTACHMENT 1

DISTRIBUTION OF CARE AND TREATMENT GRANTS / LOA PROVIDED BY THE NEW JERSEY STATE HEALTH DEPARTMENT, DIVISION OF AIDS PREVENTION AND CONTROL

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• AIDS Drug Distribution Program	Drug Therapy	HRSA	$1,926,113	Statewide
• AIDS Resource Foundation for Children	Housing	State	313,000	Ber, Ess, Hud, Mer, Mid, Mon, Mor, Oce, Pas, Som, Uni
• Burlington Comprehensive Counseling	Street Outreach/ Coordinator	State	49,000	Bur
• Center for Help In Time of Loss	Case Management	State	49,599	Ber
• Community Guidance Center of Mercer	Street Outreach/ Coordinator	State	49,500	Mer
• Community Health Care of No. Jersey	Home Care	State	123,500	Ess
• Covenant House NJ	Adolescent Outreach	State	400,000	Atl, Ess, Mer
• C.U.R.A., Inc.	Resid. Drug Treatment Beds, Mobile Outreach Vans, Street Outreach/ Coordinator	State	222,000	Statewide
• Division of Addiction Services-DOH	Case Management	HRSA	160,000	Ess, Hud
• Damon House	Street Outreach/ Coordinator	State	49,500	Mid
• Discovery Institute For Addic. Diseases	Street Outreach/ Coordinator	State	54,000	Mon
• East Orange General	Case Management/ Coordinator	HRSA	78,625	Ess
• East Orange Substance Abuse Program	Street Outreach/ Coordinator	State	57,700	Ess
• Essex Substance Abuse Treatment Center	Street Outreach/ Coordinator	State CDC	88,600 15,650	Ess
• Hope House	Buddies (Volunteer)	State	125,000	Mor
• Hyacinth Foundation	Buddies (Volunteer)	State	220,000	Ess, Hud, Hun, Mer, Mid, Mon, Oce, Pas, Som, Uni

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• Institute for Human Development	Resid. Drug Treatment Beds, Street Outreach/ Coordinator	State CDC	$426,943 15,650	Statewide
• Integrity, Inc.	Resid. Drug Treatment Beds, Street Outreach/ Coordinator	State	189,500	Statewide
• Jersey City Medical Center	Early Intervention	State	250,00	Ess, Hud, Uni
• Jersey City Medical Center	Case Management/ Coordinator	RWJ	76,163	Ess, Hud, Uni
• Jersey Shore Addict Services	Street Outreach/ Coordinator	State CDC	64,500 15,650	Mon, Oce
• Jersey Shore Medical Center	Ambulatory Care	State	249,870	Mon, Oce
• Martin Luther King Academy	Case Management	State	50,000	Cap, Cum, Sal
• Mercer County Adolescent Coalition	Housing	State	282,000	Statewide
• Morris County After Care	Street Outreach/ Coordinator	State	49,850	Mor
• Newark Beth Israel Medical Center	Ambulatory Care	State	176,448	Ess, Uni
• Newark Beth Israel Medical Center	Case Management	HRSA	36,193	Ess, Uni
• Newark Community Health Center	Case Management	HRSA	73,712	Ess
• Newark Department of Health	Case Management/ Coordinator	HRSA	20,575	Ess
• Newark Renaissance House	Mobile Outreach Van, Street Outreach/ Coordinator	State	169,000	Ess
• New Brunswick Counseling Center	Street Outreach/ Coordinator	State	63,000	Mid
• New Horizon Treatment Center	Street Outreach/ Coordinator	State CDC	46,000 6,300	Mer
• NJ Association of Correction	Housing	State	282,818	Ess
• NJ Buddies	Buddies (Volunteer)	State	129,000	Ber, Pas
• Northeast Life Skills	Street Outreach/ Coordinator	State	54,700	Pas

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• Northwestern Adult Pathway House	Housing	State	$ 235,000	Statewide
• Paterson Counseling Center	Street Outreach/ Coordinator	State CDC	63,000 15,650	Pas
• PROCEED	Street Outreach/ Coordinator	State	50,000	Uni
• Raritan Bay Medical Center	Street Outreach/ Coordinator	State CDC	58,900 9,350	Mid
• Raritan Bay Medical Center	Early Intervention	State	188,000	Mid, Mon, Uni
• Rutgers Community Education	Case/Coordinator/ Consortium	HRSA	67,766	Ess
• Somerset Drug Clinic	Street Outreach/ Coordinator	State	49,500	Ess
• Spectrum Health Care	Mobile Outreach Van, Street Outreach/ Coordinator, Medical Day Care	State CDC	208,000 60,650	Ess, Hud, Uni
• St. Elizabeth's Hospital	Case Management	HRSA	40,700	Uni
• St. Joseph's Hospital	Early Intervention	State	250,00	Ber, Pas
• St. Michael's Medical Center	Early Intervention	State	410,575	Ess
• St. Michael's Medical Center	Case Management	HRSA	41,245	Ess
• St. Michael's Medical Center	Case Management	RWJ	30,090	Ess
• Straight & Narrow	Resid. Drug Treatment Beds, Street Outreach, Medical Day Care	State	296,000	Statewide
• Substance Abuse of Southern NJ	Street Outreach/ Coordinator	State CDC	50,800 6,300	Cam
• United Hospitals	Case Management	RWJ	193,273	Ber, Ess, Hud, Mor, Pas, Som, Uni
• UMDNJ	Case Management	RWJ	91,050	Ess
• UMDNJ	Dental	State	178,000	Atl, Ber, Bur, Cam, Cap, Ess, Glo, Hud, Pas, Sal, Uni

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• UMDNJ	Early Intervention	State	$146,295	Atl, Bur, Cam, Cum, Glo
• Home Care Agencies (Not yet identified)	Home Care	HRSA	810,000	Statewide
SUBTOTAL		State Federal RWJ HRSA	$6,472,098 145,200 390,579 3,254,929	
TOTAL			$10,262,803	

ATTACHMENT 2

DISTRIBUTION OF PREVENTION, EDUCATION AND TRAINING GRANTS / LOA PROVIDED BY THE NEW JERSEY STATE HEALTH DEPARTMENT, DIVISION OF AIDS PREVENTION AND CONTROL

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• Academy of Medicine of New Jersey	Professional Training	Federal State	$131,000 61,759	Statewide
• AIDS Coalition of Southern New Jersey	General, High Risk	Federal	76,900	Bur, Cam, Glo
• American Red Cross, Camden Chapter	Professional, General, High Risk, Minority, Adolescent	State	120,000	Atl, Cam, Cap
• American Red Cross, Essex Chapter	General, High Risk, Minority, Adolescent	State	120,000	Ess, Pas
• Boys & Girls Clubs of Newark	Minority, Adolescent	Federal	108,800	Ess
• CAHACO	Minority, Adolescent	Federal	84,500	Ess
• Camden AHEC	Professional, General High Risk, Minority, Adolescent, Pastoral	Federal	144,360	Bur, Cam, Glo
• Casa PRAC	Minority, Adolescent	Federal	47,000	Cum
• CATA	Minority	Federal	64,000	Atl, Cum, Glo, Sal & Puerto Rico
• Check-Mate	Minority	Federal	51,000	Mon
• East Orange Health Department	High Risk, Minority	Federal	35,000	Ess
• Essex Substance Abuse Treatment Ctr.	General, High Risk Minority, Adolescent	Federal	30,000 (6 months)	Ess
• HRET of New Jersey	Professional Training	State	127,000	Statewide
• Hispanic Assoc. of Ocean County	High Risk, Minority, Adolescent	Federal	72,700	Hun, Mer, Mid, Mon, Oce, Som
• Hispanic Multi-Purpose Service Ctr.	High Risk, Minority, Adolescent	Federal	75,000	Pas
• Home Health Assembly	Professional Training	State	114,994	Statewide
• Martin Luther King Academy	High Risk, Minority, Adolescent	Federal	145,000	Cum

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• Newark Health and Human Services	High Risk, Minority	State	$ 58,970	Ess
• NJ Council of Churches	High Risk, Minority, Pastoral	State	180,200	Ess, Hud, Mer, Mid
• NJ PIES Newark Beth Israel	General	Federal State	187,777 175,000	Statewide
• NJ State Nurses Association	Professional Training	Federal	60,900	Statewide
• PACO	Minority	Federal	87,000	Hud
• Passaic Dept. of Human Resources	Professional, General High Risk, Minority, Adolescent	Federal	112,400	Pas
• Powhatan-Lenape Nation	Minority	Federal State	36,000 70,00	Statewide
• PRAHD	High Risk, Minority, Adolescent	Federal	84,700	Mid
• PROCEED	Minority	Federal	95,700	Uni
• Puerto Rican Congress	Minority	Federal	60,300	Statewide
• Rutgers School of Social Work	Professional Training	State	97,850	Statewide
• South Jersey AIDS Alliance	General, High Risk, Adolescent	Federal	89,000	Atl, Cap Cum, Oce, Sal
• Spanish Community Center	High Risk, Minority, Adolescent	Federal	60,000	Atl, Cap
• UMDNJ	Professional Training	State	50,000	Statewide
• Westside Red Bank Project	Minority, Adolescent, Pastoral	Federal	141,200	Mon
SUBTOTAL		Federal State	$2,080,737 $1,175,773	
TOTAL			$3,256,510	

* **Professional Training** denotes programming for medical practitioners, allied health care professionals and workplace personnel. **General Information** refers to basic HIV/AIDS information for the general public. **High Risk Prevention/Education** emphasizes risk reduction or elimination of risky behavioral practices. **Minority Prevention/Education** targets specific racial/ethnic minority communities. **Adolescent Prevention/Education** denotes school and community-based programming for youth between the ages of 6 and 17. **Pastoral Training/Education** denotes programming for interdenominational clergy and pastoral ministers.

ATTACHMENT 3

DISTRIBUTION OF COUNSELING AND TESTING SERVICES GRANTS / LOA PROVIDED BY THE NEW JERSEY STATE HEALTH DEPARTMENT, DIVISION OF AIDS PREVENTION AND CONTROL

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• Atlantic City DOH Atlantic City	HIV CTS = 8, STD = 9, TB = 7, DTC = 5, FP/PN = 9	Federal State	$ 280,735 87,735	Atl, Cap, Cum, Glo Sal
• Bergen County DOH Paramus	HIV CTS = 1, STD = 2, TB = 1, DTC = 2	State	163,225	Ber
• Burlington County DOH	HIV CTS = 1, STD = 1, TB = 1, DTC = 3, FP/PN = 6	State	104,800	Bur
• Camden County DOH	HIV CTS = 4, STD = 1, TB = 1, DTC = 5	Federal	246,052	Cam
• City of Trenton DOH	STD = 1	State	38,335	Mer
• City of Paterson DOH	STD = 1	Federal	27,000	Pas
• East Orange DOH	HIV CTS = 1, STD = 2, TB = 7, DTC = 4	State	206,240	Ess
• Elizabeth General Hospital	HIV CTS = 1, STD = 2, DTC = 2	State	123,878	Uni
• Henry J. Austin Health Center	HIV CTS = 1, STD = 2, TB = 1, DTC = 2	Federal State	166,800 18,551	Mer
• Hunterdon County DOH	HIV CTS = 1, TB = 1	State	119,697	Hun
• Hyacinth Foundation	HIV CTS = 1, STD = 1, DTC = 1	State	294,628	Uni
• Jersey City Medical Center, Jersey City	HIV CTS = 1, STD = 3, TB = 2, DTC = 1	Federal State	389,226 32,396	Hud
• Jersey Shore Medical Center, Neptune	HIV CTS = 1, STD = 2 TB = 1, DTC = 3	State	186,272	Mon
• MCH Services, Divison Community Health	FP/PN = 21	Federal State	802,000 240,000	Ess, Hud, Mer, Mid, Pas, Uni
• Middlesex County DOH	STD = 1	Federal State	36,000 1,464	Mid
• Morristown Memorial Hospital, Morristown	HIV CTS = 1, STD = 1, TB = 2, DTC = 2	State	162,208	Mor, Sus
• Ocean County DOH, Toms River	HIV CTS = 1, STD = 2, TB = 1, FP/PN = 2	State	130,299	Oce
• Spectrum, Newark & Jersey City	DTC = 2	State	54,000	Hud, Ess

AGENCY	SERVICE TYPE*	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• St. Joseph Medical Center, Paterson	HIV CTS = 1, STD = 1, TB = 2, DTC = 4	Federal	$ 289,660	Pas
• St. Michael's Medical Center, Newark	HIV CTS = 1, TB = 1, DTC = 5	Federal State	276,900 182,229	Ess, Hud
• UMDNJ, RWJ Medical Sch., New Brunswick	HIV CTS = 2, STD = 4, TB = 2, DTC = 3	Federal	351,260	Mid, Som
SUBTOTAL		Federal State	$ 2,865,338 $ 2,045,957	
TOTAL			$ 4,911,295	

* OBJECTIVE OF THE AGENCY IS **TO PROVIDE HIV COUNSELING AND TESTING (C&T) TO THE POPULATION AT RISK OF CONTRACTING THIS INFECTION**. THIS IS DONE BY DIFFERENT TYPES OF CLINICS: HIV CTS = Provide only HIV C&T, STD = Sexually Transmitted Disease, TB = Tuberculosis, DTC = Drug Treatment Center, FP = Family Planning, PN = Prenatal, OTHER = Other health departments and clinics.

ATTACHMENT 4

DISTRIBUTION OF HIV/AIDS RESEARCH GRANTS / LOA PROVIDED BY THE NEW JERSEY STATE HEALTH DEPARTMENT, DIVISION OF AIDS PREVENTION AND CONTROL

AGENCY	RESEARCH TYPE	FUNDING SOURCE	AMOUNT	COUNTY(S) SERVED
• Central Jersey Blood Bank	HIV seroprevalence among blood donors	Federal	$ 1,300	
• Division of Epid.	HIV seroprevalence and Risk Behavioral studies at STD clinic	Federal	64,630	
• Essex Substance Abuse Center, Nwk.	HIV seroprevalence and Risk Behavioral studies at drug treatment clinics	Federal	39,715	
• Institute for Human Development	HIV seroprevalence at drug clinic	Federal	3,150	
• New Brunswick Counseling Center	HIV seroprevalence at drug clinic	Federal	2,450	
• North Jersey AIDS Alliance	Community Research Initiatives to perform clinical trial of therapies related to HIV	State	80,000	
• North Jersey Blood Center	HIV seroprevalence among blood donors	Federal	55,644	
• Paterson Counseling Center, Paterson	HIV seroprevalence at drug clinic	Federal	3,150	
• Planned Parenthood of Essex	HIV seroprevalence at Family Planning clinic	Federal	9,000	
• Planned Parenthood of GN New Jersey	HIV seroprevalence at Family Planning clinic	Federal	9,000	
• Spectrum Jersey City/ Newark	HIV seroprevalence and Risk Behavioral studies at drug treatment clinic	Federal	40,750	
• Substance Abuse of So. Jersey, Camden	HIV seroprevalence at drug clinic	Federal	2,450	
• UMDNJ, Community	Prospective cohort	State	58,000	
• UMDNJ, Immunology Laboratory	Immune function study (service to transfusion study)	Federal	12,500	
SUBTOTAL		Federal State	$ 243,739 $ 138,000	
TOTAL			$ 381,739	

DEPARTMENT OF HEALTH: OTHER DIVISIONS

As of 1990, five divisions, in addition to the Division of AIDS, conduct HIV/AIDS-related activities: Public Health and Environmental Laboratories; Epidemiology and Disease Control; Occupational and Environmental Health; Alcoholism, Drug Abuse and Addiction Services; and Family Health Services, which includes the Family Planning Program, Maternal and Child Health Services, the Pediatric AIDS Network, the Perinatal AIDS Prevention Project, and Maternal and Infant Health. Two other divisions, Health Planning and Resources Development (HPRD) and Health Facilities and Evaluation (HFE) also are involved in HIV/AIDS issues through administration of the DRG system, certificates of need, and licensing and inspection services.

- **Division of Public Health and Environmental Laboratories**

This division conducts HIV screening tests for the state and for federal projects. From November 1989 through October 1990, the AIDS testing unit screened 92,000 specimens for the presence of antibodies to HIV using the enzyme immunoassay (EIA) tests, and confirmed 7 percent of those repeatedly reactive specimens with the Western Blot procedure. About 90 percent of these specimens were evenly distributed between Counseling and Testing site collections and the CDC Family of Surveys. The remaining specimens represent a number of diverse services and studies being conducted by other divisions and agencies. Those include drug outreach, alcohol abusers, and state medical examiner specimens.

Laboratories are also conducting a variety of other studies related to HIV/AIDS issues.

The total amount of FY91 projected to be spent on HIV services and therefore reimbursed as revenue for this Division was $1,059,000, of which $121,000 was state and $937,000 federal revenue.

- **Division of Epidemiology and Disease Control**

Most of the HIV/AIDS activities in this division are under the Tuberculosis (TB) and Sexually Transmitted Disease (STD) Control Programs. The one exception is the Rape Care Program, which has received federal funds through the State Law Enforcement Planning Agency to provide HIV/AIDS and STD information to victims of rape. Among the studies funded by grants are: HIV/TB Cohort Study and HIV/TB Autopsy Study; HIV/Syphilis Partner Notification Study; the CDC Family of Surveys Blinded and Non-Blinded Studies; TB/AIDS Registry Match; HIV-Related Demonstration Project; HIV Counseling and Testing in Newark's STD Clinic; and HIV/AIDS/STD information for rape victims.

The total FY91 amount budgeted for HIV/AIDS-related services in this division was $1,677,000, all in federal funds.

- **Occupational and Environmental Health**

This division is involved in two areas of HIV/AIDS-related activities: a federally funded study to identify the frequency and nature of episodes which could pose an occupational risk of exposure to HIV and HBV (Hepatitis B virus) infection among correctional workers, which has just been completed; and the distribution of "AIDS and Emergency Responders: An Informational Booklet," published by the Public Employees Occupational Safety and Health (PEOSH) Program. This booklet was compiled with input from the division, and is distributed to unions, municipalities, state agencies, schools, and other interested parties.

When the federal Occupational Safety and Health Administration finalizes Section 1030, Bloodborne Pathogens, of 29 CFR 1910 (federal regulations), this regulation will be adopted for New Jersey public employees, and will necessitate inspection, enforcement, and educational activities by the division.

The total FY91 amount budgeted for AIDS services for Occupational and Environmental Health was $41,000, of which $11,000 was state funds, and $30,000 federal funds.

- **Alcoholism, Drug Abuse and Addiction Services**

Addiction Services has only a few HIV/AIDS-related activities, since most were transferred to the Division of AIDS at its inception. The division has awarded contracts for the following services: AIDS Counseling and Testing for three drug treatment clinics; Drug Counseling Referral in a Family Health Care project in Newark; the Newark/Jersey City Health Behavior Project; and the Paterson Health Behavior Project.

The total FY91 amount budgeted for this division for HIV/AIDS activities was $2,231,000, all in federal funds, with $45,000 of that transferred from the Division of AIDS.

- **Family Health Services**

This division embraces several HIV/AIDS-related programs.

- The division received a grant from the CDC conduited through the Division of AIDS to conduct HIV-related services (counseling and testing) in family planning agencies, under the aegis of the Family Health Services Family Planning Program. Over the past two years, information and education on HIV/AIDS has been provided to over 100,000 women. The total FY91 amount budgeted for this activity was $834,000, of which $32,000 were state funds, and $802,000 federal funds.

- Another activity within this division is integration of HIV/AIDS educational activities in the form of workshops and newsletters in reproductive health services through the Family Planning Program. The FY91 amount budgeted for this task was $30,000, all state funds, which is reflected under the Maternal and Infant Health dollars in the summary attachment.

- Pediatric HIV Network

  A network of community-based, family-focused coordinated services has been established in New Jersey for infants and children with HIV infection. In addition, a pediatric HIV resource center was developed as a component of the Children's Hospital AIDS Program (in Newark). Four regional (Camden, Jersey City, New Brunswick, Paterson) and two affiliate centers (Newark, Atlantic City) have been funded, and there is a third non-funded site in Monmouth County. The centers serve as the focal point in their region for the care of children with HIV infection. The services provided include health care, outreach, education, building of community coalitions, and linkage with appropriate community services. Case managers at each regional center work closely with children and families to develop a plan to meet their needs. The total FY91 amount budgeted for the Pediatric HIV Network was $979,000, all federal funds.

- Perinatal AIDS Prevention Project

  A five-year research and demonstration project was funded in New Jersey by the CDC as one of eight nationwide projects under Perinatal HIV Reduction Education and Demonstration Activities. The ultimate goal of this project is to reduce the number of children who are infected perinatally with HIV. Because currently there is no way to

prevent transmission of the virus from an infected pregnant woman to her unborn child, reduction can only be accomplished through education aimed at preventing women from becoming infected, or aimed at infected women not becoming pregnant. The major focus of New Jersey's study is to help HIV-infected and high-risk women become aware of the risks of perinatal transmission. The project's efforts are designed to give women the information they need to make an informed decision and access to needed services. The total FY91 amount budgeted for this project was $900,000, all federal funds.

- Maternal and Infant Health

  This program funds six perinatal centers to provide statewide, comprehensive high-risk prenatal services. The services include high-risk obstetrical projects, Fetal Alcohol Syndrome Prevention projects, and the coordination of perinatal addiction treatment projects.

  Supported by state funds transferred from the Division of AIDS, the high-risk perinatal centers provide HIV and AIDS education, HIV-infection counseling, and offer HIV testing to all clients enrolled in their prenatal clinics. The total FY91 amount budgeted for this activity was $210,000, all state funds.

- **Health Planning and Resources Development**

HPRD is involved in HIV/AIDS-related activities as part of its normal activities, which embrace hospital reimbursement and health planning through the certificate of need (CN) process. Reimbursement evaluates cost and utilization data on acute care hospital services to HIV/AIDS patients sets HIV/AIDS DRG rates and is investigating construction of new rates for early intervention services in the outpatient setting.

Health Planning evaluates and recommends positions (with input from the Division of AIDS) to be taken on CN applications to initiate or expand services to HIV/AIDS patients and adds conditions to CN applications to ensure facility compliance with the Department of Health guidelines that provide for full access by HIV/AIDS patients, and integration within the state continuum-of-care networks. Currently, there is one convalescent center with 120 long-term care (LTC) beds dedicated to HIV/AIDS patients (70 beds are occupied); a 16-bed AIDS patient residential health care facility; two medical day care programs, one with 36 and the other with 35 spaces; and two other CNs in review--

one for a 20-bed unit at a 281-bed long term care facility, the other for a 16-bed short-term (average length of stay 30 days) subacute unit.

- **Health Facilities Licensing and Evaluation**

This division is charged with the licensing and evaluation of health care facilities. As part of its ongoing work it inspects the licensed subacute health care facilities for HIV/AIDS clients. It also inspects acute care general hospitals, and respond to complaints about facilities.

SUMMARY

The FY91 amount budgeted for HIV/AIDS-related services by the different divisions in the Department of Health is $34,833,000. A summary by division is included as Appendix VII. Dollars transferred from the Division of AIDS to other divisions were identified and not double-counted.

STATE GOVERNMENT RESPONSE: OFFICE OF THE GOVERNOR

The Office of the Governor, as the Executive Office of State Government, has an ongoing involvement in HIV/AIDS issues as they pertain to policy matters and the functioning of State Government.

New Jersey State Government is comprised of the Office of the Governor, 19 departments and various commissions and agencies. The departments involved in HIV/AIDS-related activities are, in addition to Health: Community Affairs; Corrections; Education; Higher Education; Human Services; Insurance; Labor; Law and Public Safety (Office of the Attorney General); Personnel; and the Public Advocate. Of these 11 departments, four -- Corrections, Education, Human Services, and Health -- have specific dollars directed towards HIV activities. In the other departments and offices such activities are handled as a matter of normal business, and have no specific budget or staff attached.

STATE GOVERNMENT RESPONSE: OTHER DEPARTMENTS

- **Department of Corrections**

Corrections administers state and county correctional facilities, and oversees municipal facilities. It has responsibility for direct inmate care, including HIV/AIDS, which is mandated under N.J.A.C. 10A:16. There are two other areas of involvement--an AIDS Awareness Program, mandated by a Governor's Executive Order, and implemented through the Department of Personnel and the Department of Corrections' Office of Human Resources; and reporting of AIDS cases to the Department of Health and the CDC.

Testing and counseling is usually done for symptomatic inmates, inmates who are pregnant, and inmates on dialysis. In the near future, testing will be done for all inmates who request it. Those who are HIV-positive receive CD4 counts, doctor visits, AZT, aerosolized pentamidine and other therapies provided by the department. "Local rule" affects the standardization of policies, services and treatment provided to inmates across the state, county and municipal facilities. This is problematic, because it means that testing, counseling and provision of medical care and therapies vary by correctional site, and may not be provided at all at some sites. Acute care services for Department of Corrections inmates with HIV/AIDS are provided by St. Francis Medical Center in Trenton.

The total amount projected for provision of care in FY91 was $8,150,000, all state funds.

- **Department of Education**

Education has placed its HIV/AIDS Prevention Education Program in the Bureau of Student Behavior and Development. The bureau is responsible for programs which assist local school districts in meeting the social and health needs of students in elementary, middle, and high schools. Additional programs address substance abuse prevention and education, family life education, alternative education, teen pregnancy, school health education and character and value development programs. Although the department has issued HIV/AIDS education guidelines, the autonomy of local school boards determines the time allotted to and the method of teaching HIV/AIDS material.

The department received a grant from CDC for $342,000 for the implementation of its AIDS prevention/education effort. Six full-time staff are associated with this activity.

- **Department of Human Services**

The major divisions within Human Services involved in HIV/AIDS activities are the Divisions of Youth and Family Services (DYFS) and Medical Assistance and Health Services (DMAHS-Medicaid). DMAHS provides Medicaid services to all individuals meeting financial and medical necessity requirements, regardless of diagnosis. Certain services are mandated; others are provided at the option of the state.

New Jersey Medicaid expends money on treatment of HIV/AIDS-infected persons, and on drugs and devices as part of its regular benefits. Medicaid also funds the AIDS Community Care Alternative Program (ACCAP) under a Medicaid waiver, and has served 1,765 clients since March 1987. It is funded with 50:50 federal: state funds for a total of $27,000,000 for FY91. New Jersey Medicaid also has a federal grant of $1,300,000 for an ACCAP evaluation. Another HIV/AIDS initiative is an enhanced rate for basic services and special services for Medicaid clients at Wanaque, the 120-bed long-term care facility.

DYFS is established under state statute and follows federal guidelines in administering some programs. The Medical Unit is the locus of responsibility for all child health issues, including HIV infection.

DYFS provides funds to a variety of programs: group homes such as the AIDS Resource Foundation for Children, O'Neill Home, and Dooley House for children with HIV; The Family Place, a consortium of agencies which provides a variety of services including case management, respite care, foster parent training, and counseling; pediatric nursing service assistance for children who are HIV-infected; case management in the

Children's Hospital AIDS Program at United Hospitals; Babyland Nursery, a pediatric day care center; and training and community education.

The total budgeted for DMAHS for FY91 was $28,400,000, of which $13,550,000 was state funds and $14,850,000 federal. The total budgeted for DYFS was $3,388,000, of which $1,228,000 was state funds and $2,160,000 federal.

The FY91 total budgeted for the Departments of Corrections, Education, Human Services, and Health for specific HIV/AIDS activities was $75,113,000. A summary is included as Appendix VII.

The other departments' activities are conducted within the framework of their existing programs.

- **Department of Community Affairs**

Within the Department of Community Affairs, the Division on Women and the Division on Housing, through the Bureau of Housing Services, are involved in HIV/AIDS-related activities. The Division on Women attended a recent conference on pediatric AIDS. The Division of Housing, through the Bureau of Housing Services, administers the U.S. Department of Housing and Urban Development Section 8 Housing Program, which is mandated to provide safe, decent and sanitary housing for very low-income individuals. Tenant selection is based on eligibility criteria, not on the nature of any disability or handicap.

- **Department of Higher Education**

Three offices/programs in the Department of Higher Education are involved with HIV/AIDS issues. The Office of Institutional Relations handles the affairs of four-year and graduate institutions, public and private, which include three universities, nine state colleges and 26 independent institutions,and a variety of grants and contracts. The Office of Community Colleges handles matters affecting 17 community colleges and two county commissions and administers grants to colleges for vocational education. The Educational Opportunity Fund Program provides programmatic funds to colleges and direct grants to students who are educationally and economically disadvantaged. Additionally, a letter of agreement between the Departments of Higher Education and Health calls for refinement of a New Jersey manual and policy guidelines for dissemination by the State Board of Higher Education; coordination of four types of seminars and training events; support

of a network of campus HIV coordinators and the dissemination of educational materials, all designed to address HIV/AIDS issues.

- **Department of Insurance**

Three divisions of the Department of Insurance have been involved in HIV/AIDS issues: Actuarial Services, Life and Health; Legislative and Regulatory Affairs; and the License, Enforcement and Consumer Protection Division. The Actuarial Services Division, in its normal review of life and health insurance policies, prohibits policy provisions which exclude benefits for the treatment of AIDS or otherwise treats AIDS differently from other conditions. This division also responds to coverage questions.

The Division of Legislative and Regulatory Affairs drafts regulations and also responds to inquiries concerning requirements of the regulations, and any bulletins. The License, Enforcement and Consumer Protections Division investigates consumer complaints about AIDS issues and takes actions against insurers or agents engaged in improper activities. This division also responds to inquiries about policy availability and coverage for people with HIV/AIDS.

- **Department of Labor**

The Department of Labor is involved with HIV/AIDS activities through its training of state employees, and training of staff in its 132 local offices. It has carried out an AIDS Awareness Program which consisted of guidelines for employees and co-workers, and guidelines for serving the public. It also administers an ongoing program of treatment of renabilitation clients through the Division of Vocational Rehabilitation, and a program of medical evaluation for HIV infection, through the Division of Disability Determinations.

- **Department of Law and Public Safety (Office of the Attorney General)**

The nature of the Department of Law and Public Safety's involvement with HIV/AIDS issues is largely in the area of third-party exposure, agency advice/litigation and legal/civil rights. In particular, the Division of Law and Civil Rights addresses those matters concerning the legal/civil rights of HIV-infected persons. Critical issues are confidentiality and discrimination, and resolution of these issues lies at the base of major policy decisions which must eventually be taken in reference to an HIV/AIDS plan. To date, the number of lawsuits addressing these issues has been limited.

The Division of Consumer Affairs has issued regulations and policies through its professional regulatory boards which, in general, require licensees to provide services to HIV-positive individuals. The Board of Dentistry, the Board of Medical Examiners, and the Board of Optometrists have issued policy statements; the Board of Pharmacy requires five continuing education credits in AIDS education for re-licensure in 1991; the Board of Mortuary Science is promulgating regulations concerning funerals of deceased persons with HIV/AIDS; and the Board of Medical Examiners held a seminar in December, in conjunction with UMDNJ, on "the HIV-Positive Individual and the Health Professional."

The State Medical Examiner's Office utilizes a training seminar developed by UMDNJ and tailored to forensic pathologists, morgue technicians, and related occupations. The program was offered in conjunction with UMDNJ and supported by a grant from the Health Resources and Services Administration. The Medical Examiner's Office also provides continuing education in conjunction with the Regional Education and Training Center at UMDNJ.

The Division of Civil Rights is mandated to enforce two state laws which could pertain to HIV-infected persons: N.J.S.A. 10:5-1 et seq., which prohibits discriminatory practices in employment, housing, and public accommodations and specifically prohibits discrimination on the basis of a handicap; and N.J.S.A. 10:5-12.2 et seq., which prohibits a skilled nursing or intermediate facility from denying admission to a qualified applicant. The AIDS-related complaints which this division has handled were based on alleged employment, housing and public-accommodations discrimination.

- **Department of Personnel**

Personnel is the executive agency responsible for providing human resource management to agencies of state government, and to county and municipal units that are part of the state civil service system. The components of this department that deal with HIV/AIDS-related issues are the newly-formed Human Resources Development Institute, which provides HIV/AIDS training to employees and which will have the responsibility for training employees of state institutions that deal with HIV-infected patients. The department also has, through its Employee Advisory Service, a counseling and referral service for state employees and their families which provides services for HIV-infected individuals as part of its assistance program.

- **Department of the Public Advocate**

The Public Advocate is a publicly funded law office which represents the citizens of New Jersey in civil and criminal proceedings. Civil representation occurs in the Division of Advocacy for the Developmentally Disabled, Division of Mental Health Advocacy, Division of Rate Counsel, Division of Public Interest Advocacy, and the Division of Citizens' Complaints and Dispute Resolution. Criminal matters representation occurs in the Office of the Public Defender, Office of Inmate Advocacy, Office of the Law Guardian, and in the Parole Revocation Defense Program. All of these divisions have experienced an increase in HIV/AIDS-related concerns.

THE ECONOMIC COST OF HIV/AIDS

BEST COPY AVAILABLE

THE ECONOMIC COST OF HIV/AIDS

COST TO NEW JERSEY

The HIV/AIDS epidemic has had, and continues to have, significant economic impact both on the State of New Jersey and on the nation. New Jersey government, hospitals, insurance carriers, businesses and individuals have been affected. The fiscal impact will only grow as the AIDS caseload increases.

On the national level, numerous studies have explored the economic effect of the HIV/AIDS epidemic. However, the effect varies as medical care changes, and as more information is gathered, all of which tend to date the studies. Most of these studies have been done on small numbers of a specific population, at a specific hospital or in a small geographic area, and are usually conducted on patients with AIDS, not on asymptomatic HIV-positive persons.

Any cost projection, therefore, depends on estimates of the number of persons infected with HIV; survival time; the type of patients studied; the severity of their illnesses; the state of medical care; the utilization of services; and the dollars spent. Further comprehensive studies should be conducted in various areas and on various populations. We can never have too much data.

The economic impact of the HIV epidemic embraces both direct and indirect costs. Direct costs include personal medical care (hospital stays, physician costs, inpatient and outpatient services' ancillary services, nursing and home health care, respite and hospice services) as well as nonpersonal direct expenditures such as biomedical research, health education campaigns, blood screening and testing, and support services; indirect costs include the loss of wages as a result of illness and disability and the loss of future earnings as a result of premature death. The loss of future productivity is expected to be substantial in many instances because HIV infection primarily strikes young adults in their most productive years (1).

The latest published article by Hellinger (2) includes estimates of the lifetime cost of care for a person with AIDS (inpatient, outpatient and out-of-pocket drug costs) at $75,000 in 1988 dollars. This assumes an average survival time from diagnosis to death of 15 months, no change in the level of care, 2.74 hospitalizations per year, and an average length of stay for each of 15.85 days. Hellinger projected the following:

PROJECTED TREATMENT COSTS FOR NEW CASES

Year	New Cases Diagnosed	Treatment Costs
1990	56,000	$4,300,000,000
1991	70,000	5,300,000,000
1992	87,000	6,500,000,000
1993	104,000	7,800,000,000

Seage estimates a lifetime medical cost of $42,399 for a person with AIDS (3). If this amount is applied to the number of cases already diagnosed (157,525 as of December 31, 1990), the cost of medical care for these cases would be over $6.6 billion nationally.

Projections of indirect costs are much more difficult because of the inaccuracies inherent in predicting life-span, earnings, and the number of cases. Two studies, though, have estimated the indirect costs. Hardy approximates the indirect costs of the first 10,000 AIDS cases at $4.8 billion (4); Scitovsky and Rice estimate the indirect costs at $7 billion in 1986 and at $55.6 billion in 1991 (1).

The cost of caring for children with AIDS was described by Andrulis in a March 1990 report based on a 1987 hospital pediatric AIDS survey. The annual cost of caring for a pediatric AIDS patient was $34,713, and one in ten days was deemed medically unnecessary. (The "unnecessary days" were due to lack of family or foster care for these HIV-positive children). (5)

COST TO STATE GOVERNMENT

In the previous section, the current amounts budgeted by the State of New Jersey for HIV activities were described in detail. These amounts may be compared with the amounts spent in Fiscal Year 1986 (July 1, 1985 -June 30, 1986):

COMPARISON OF FY 86 AND FY89 STATE HIV-RELATED DOLLARS

FY 86	Department	Amount Spent
	Health	$2,000,000
	Corrections	2,000,000
		$4,000,000
In FY91, the expenditures leaped:		
	Health	$34,833,000
	Corrections	8,150,000
	Education	342,000
	Human Services	31,788,000
		$75,113,000

The figure for Human Services (Medicaid and DYFS) does not include Medicaid payments for treatment and for drugs/devices, which may come to an additional $20,000,000. In other state departments, such as Community Affairs and Insurance, HIV-positive persons are considered a part of the regular populations served, and the cost is included in normal operations.

COST TO HOSPITALS AND THE HEALTH CARE SYSTEM

In New Jersey, as described in previous sections, the majority of cases of AIDS has occurred among IVDUs. Many IVDUs have a variety of other health problems, and lack access to health care and funds to pay for it. Many do not seek care until they become acutely ill; consequently, the primary source of care for these IVDUs is a hospital emergency room. This situation is exacerbated by the concentration of AIDS cases in inner-city populations.

Acute care hospitals were among the first in the state to feel an economic impact from the HIV epidemic. New Jersey's system of hospital reimbursement is based on grouping medical diagnoses into clusters called Diagnosis Related Groups (DRGs). An average rate for each DRG, based on the hospital's historical data, is set for each acute care general hospital.

The average rate for a DRG is meant to cover the costs of caring for a "typical" patient. Since this represents an average, some patients actually consume less, and others more, resources than the DRG amount, but the hospital can bill only the DRG rate.

Until 1989, there were no DRGs specifically designated for HIV infection or AIDS, so HIV-positive patients were assigned to a DRG that reflected the reason they came to the hospital; e.g., pneumonia, anemia, skin lesions. However, HIV-infected patients tend to use considerably more resources than non-HIV-infected patients in those DRGs. And because hospitals can only bill the DRG rate, many hospitals were losing money on each AIDS patient they treated.

From 1986 to 1989, efforts were made to quantify and adjust hospital payments for the added costs of caring for patients with HIV/ AIDS. Finally, in 1989, 12 HIV-related DRGs (developed in New York) were implemented for hospital reimbursement in New Jersey. During 1989, hospitals billed daily rates (per diems) for those 12 DRGs; in January 1990, DRG rates were available and in use for the 12 HIV-related DRGs.

In both the inpatient and outpatient settings, acute care hospitals have seen a substantial increase in the number of HIV-infected persons who cannot pay their hospital bills. Under New Jersey's DRG system, a dollar amount is added to each bill to cover the cost of providing care for those who cannot pay. Currently, that money goes into the Uncompensated Care Trust Fund, from which hospitals that need to cover their uncompensated costs can draw. The Trust Fund has been a crucial part of New Jersey's DRG system; patients are not turned away from acute care hospitals in the state because of their inability to pay. But as more patients have come in with AIDS-related illnesses, and more of these patients have been unable to pay their bills, a strain has been placed on the Trust Fund. In part because of the increase in AIDS patients and the resulting increase in uncompensated care, hospitals have appealed for an increase in their rates, which has further strained the Fund. (As of this writing, the Fund has lapsed, but negotiations are underway that may allow it to continue in some form.)

The following is a summary of the Trust Fund experience:

TRUST FUND DOLLARS REQUIRED BY YEAR

Year	Fund Dollars Needed	
1983	$ 233,000,000	
1986	366,000,000	
1989	578,000,000	(estimated)
1990	718,000,000	(estimated)
1991	912,000,000	(estimated)

In New Jersey, where many of the persons with AIDS and HIV infection are indigent, the cost of hospital care has to be covered by public payers, if the patient is eligible, or by the Trust Fund. In 1986, data from six acute care hospitals showed the following payer mix in 1,456 HIV-related discharges in that year:

SOURCE OF PAYMENT FOR HIV-RELATED DISCHARGES, 1986

Payer	Percent of Patients
Medicaid	37%
Self-pay	23%
Other Government	21%
New Jersey Blue Cross	7%
Medicare	6%
Commercial Insurance	3%
New York Blue Cross	1%
Other	2%

According to the 1986 Department of Health study, half of the self-pay patients eventually qualify for Medicaid, and the costs of about one-third of the self-pays are covered by the Trust Fund (6). The total dollars billed for those 1,456 discharges amounted to $16,289,758--an average of $11,188 per inpatient visit. The range of bills was approximately $8,000-$14,000. The average length of stay for these cases was 20.9 days. The total charges were $17,200,745, or an average of $11,814 per discharge, which represented an average loss of $626 on each visit.

In 1989, the same six hospitals had 2,167 discharges related to HIV infection and billed $23,579,016, or an average of $10,881 per inpatient visit. The average length of stay was 20.4 days, and the total charges were $23,770,838, or an average of $10,969 per visit, which is approximately the amount billed.

The total amount billed in 1989 in all 86 New Jersey acute care hospitals for HIV-related inpatient care was $70,004,334 for 5,840 discharges. The average bill was $11,987, with a range of $9,000-$20,000. The slight differences in the percentage of patients for each payer between 1986 and 1989 for these six hospitals may be due to the differences in the definition of AIDS between 1986 and 1989, and the implementation of HIV-specific medical codes in 1987. On the other hand, the differences could be due to an increasing burden on Medicaid.

SOURCE OF PAYMENT FOR HIV-RELATED DISCHARGES, 1989

Payer	Percent of Patients
Medicaid	41%
Self-pay	21%
Other Government	19%
New Jersey Blue Cross	7%
Medicare	4%
Commercial	3%
Other	5%

Preliminary data obtained from TAP, New Jersey's early intervention program, showed an average of two to three visits per client in about six months and an average bill of $212 per visit. However, these averages are not based on a full year's data and the number of visits will vary. The $212 includes hospital-based services such as clinic, lab, radiology, and aerosolized pentamidine. It does not, however, include the cost of therapy or drugs, such as AZT or Bactrim, obtained from an outside pharmacy. Nor does it include other costs to the client, such as home health care, or fee-for-service physician costs. (The percentage of insured clients varied by TAP site from 26% to 74%).

Other studies have demonstrated a higher number of outpatient visits by clients. A Division of AIDS survey of outpatient/ambulatory clinic visits by HIV-positive persons in 1988 showed that there were 5.7 outpatient visits per client per year. In a study of nine sites, Fleishman (7) found the average number of outpatient visits to be 12.73 and the average outpatient charge $3,867 per year. Clearly outpatient, ambulatory care, when appropriate, is a less expensive option. More hard data is needed from inpatient and outpatient settings to accurately track the economic impact of the HIV epidemic on hospitals, and on the health care system in New Jersey.

- **COST TO INSURANCE CARRIERS**

Financial coverage for the care of HIV-positive persons is problematic in New Jersey. This is not unique. Hospital services tend to be covered by insurance more than other services, and in New Jersey the Trust Fund has covered the cost of providing care to those who cannot pay. The situation is quite different in the out-of-hospital care arena, as many insurance carriers do not cover outpatient or out-of-hospital services. An added problem is that

many asymptomatic HIV-infected persons who have insurance prefer to pay for care themselves, rather than have their insurance company learn that they are HIV-positive.

As with the rest of the country, there are difficulties with coverage for HIV-infected persons. Private carriers may exclude AIDS-related conditions from coverage, put limits on the amount of reimbursement for AIDS services, or charge exorbitant premiums for groups which are considered by the insurance company to be at risk for having possible, or potential, cases of AIDS. A number of insurance companies also include pre-existing condition exclusion clauses in their policies, although these restrictions tend to occur in individual rather than in group policies.

The Office of Technology Assessment (OTA) conducted a 1987 survey of of commercial insurers, Blue Cross/Blue Shield plans and Health Maintenance Organizations (HMOs). The focus of the survey was the individual policies written by these carriers. Seventy-seven of the 83 commercial carriers, 15 Blue Cross/Blue Shield plans, and 39 of the 50 HMOs responded. AIDS was a major concern. Many had clauses designed to limit their losses. However, when asked to rank the conditions that had absorbed the most claim dollars, AIDS and AIDS-related illnesses were ranked #16 among the commercial carriers and #14 among the Blue Cross/Blue Shield plans. (The HMOs did not provide enough information for a ranking.) The top four costliest conditions were circulatory disorders, neoplasms, respiratory and digestive disorders. (8)

A 1990 study of AIDS-related claims paid in 1989 was conducted by the American Council of Life Insurance and the Health Insurance Association of America. A total of 301 companies responded, and the results covered 65% of total industry life and health insurance claims from all causes. Respondents paid over $659,000,000 of AIDS-related claims in 1989, but only 1.7% of the total ordinary life death claims and 2.5% of the group life claims were AIDS-related. Reported AIDS-related accident and health insurance claims were 1.3% of total individual and 1.4% of total group claims. The average AIDS-related life insurance claim was $28,200 for ordinary and $34,200 for group. (9)

One of the large insurance carriers in New Jersey has provided the following information on its experience with AIDS-related hospital inpatient claims:

AIDS-RELATED HOSPITAL INPATIENT CLAIMS

	1986	1987	1988
Number subscribers with AIDS	250	708	926
Total hospital admissions	332	1,007	1,307
Average admissions per person per year	1.33	1.42	1.41
Total hospital days	6,385	16,676	18,130
Average length of stay (days)	19.2	16.5	13.9
Total claim dollars	$2,600,000	$7,900,000	$9,900,000
Average claim per admission	$7,831	$7,826	$7,567

In terms of services, New Jersey is considered a "liberal" Medicaid state, despite low individual provider payments (especially for physicians). This low reimbursement has caused some providers to refuse to accept Medicaid clients as patients. The Medicaid payment for a physician specialist is $16 ($14 for a non-specialist) which ranks New Jersey 48th among the 50 states.

To add to the equation, there are waiting times and eligibility requirements for entitlements, such as Medicaid, SSI, Medicare and public assistance. The Social Security Administration (SSA) uses the CDC definition of AIDS for disability eligibility, which has resulted in the exclusion of asymptomatic HIV-positive persons from disability entitlements, even though they may not be able to work.

The anticipated expenditures on HIV/AIDS services by New Jersey Medicaid in FY91 are expected to be in excess of $48,400,000.

COST TO BUSINESS

Premiums for health coverage for business have also risen, and many businesses have opted to become self-insured. These self-insured groups are not regulated by the Department of Insurance. Businesses have also implemented managed care programs and utilization review in an attempt to contain health care costs. Several surveys of business groups have found that, in some companies, employees with AIDS are treated as are other chronically and terminally ill workers. The 1988 Business Roundtable Survey of 118 companies indicated that the average group health benefit paid per year per employee with AIDS was $37,100, and the average group life benefit paid per employee who died of AIDS was $50,900 (10).

Information on the AIDS-related experience of New Jersey business could not be obtained in time for inclusion in this report.

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THE HUMAN COST OF HIV/AIDS

What is the human cost of HIVIAIDS in the State of New Jersey? People from every country, from every walk of life, have been infected. Tragically, the families of the infected are afflicted as well.

Marsha, a 27-year-old married woman from South Jersey, had no idea it could happen to her.

She and her husband applied for life insurance. As part of a routine procedure, they were tested for HIV. She was turned down; she had tested positive for HIV.

"I was devastated. I always thought I would get married and have children. But now children are out of the question. That's the hardest part."

Marsha said she wouldn't dream of having children and putting them at risk of HIV. But even if they wouldn't contract the disease, she said she couldn't think of leaving behind a husband and children.

"What if I didn't live?"

She believes she contracted the disease about five years ago during a short-term relationship with an IV drug user. She knew of his abuse, but the AIDS issue was not as much in the forefront at the time.

Marsha's husband has not tested positive. They are practicing "safe sex" and he is being tested every six months. Marsha is undergoing prophylactic treatment. She also is active in AIDS support groups.

"Hopefully I have another two to five years. Or maybe the treatment will prolong my life. Whenever I have a question---Should I do this or buy that?--I do it. I definitely live for today."

Marsha is most angry about the discrimination she has faced and the lack of support for women with AIDS.

In addition to being turned down for life insurance, she has been turned down by several dentists when she sought emergency treatment.

"People treating us like lepers has to be addressed."

She also maintained that there are not enough support services for women, who also are not being utilized enough in research.

She feels somewhat alone in her predicament, saying that most people she has met through the support groups are members of one of the high risk groups.

"That's what makes this much harder to deal with."

Forty-two-year-old Robert moved back with his mother last year. That was after he was in the hospital with growths in his nose. . . and after his girlfriend died of pneumonia. . .and after his girlfriend's parents booted him out of their home. . . and after he was diagnosed with AIDS.

"Everything was like a spring popping. It all happened at once."

Robert, who lives in the North Jersey, said he was an intravenous drug user about 10 years ago, but cleaned up his act and went on to college. His girlfriend did not use drugs.

"She was a good girl. I was the bad link."

He's lost most of his old friends. "You're just not invited anymore. . . or when they offer you a drink, they bring it to you in a plastic cup." And he's lost a lot of energy and 57 pounds.

But he's gained a new outlook on life.

"Everything counts. If you're making a salad, you cut the tomato the way you want."

He says he's also using what he learned in the Marine Corps.

"They condition you to a way of thinking. They tell you to hold up the bucket. You don't know how you'll do it for five minutes, but somewhere you find the strength to hold it up for an hour. You learn you can go that extra step."

Robert's primary concern is finding a place to live so he's not as much of a burden on his mother. But decent housing is difficult to come by on his limited income.

Additionally, he would like to see some work options that would not jeopardize his disability payments.

"If you make money, they take money away. I'd like to see some work option. . . may be just an hour or two a day. . . something just to fill the hours."

Marilyn and her husband had just celebrated the move into their first house in the spring of 1988 when the South Jersey family suffered a staggering blow.

Four months pregnant, Marilyn learned she had tested positive for HIV. Blood tests done on her husband, a long-time intravenous drug user, and her one year-old son showed they, too, were infected with the AIDS virus.

Worse yet, Marilyn recalls, doctors advised her that if she did not abort her unborn baby, "I'd be dead in a year." She refused the abortion because "no one could guarantee me that the baby would be sick." The child, a girl now two, is currently testing negative for HIV infection. Another child, an 11-year-old son from a previous marriage, has not been infected with HIV.

But in September 1990, her little boy died. He was three. Less than three months later, AIDS killed her 31-year-old husband.

"Nobody can imagine what we've been through," says Marilyn, 33. "I get a sore throat and I think, Is this it? Is this how it comes?" She prays she'll live to see her son and daughter grow up.

"But if I get to the point where I'm dilapidated, I'll move in with my parents" both of whom are in their 50s and live out-of-state.

The family lost Medicaid benefits when her husband died. "And my husband didn't believe in life insurance. By the time he finally decided to believe in it, he was sick and no one would insure him."

With two children to provide for, Marilyn has no job and no health insurance. The family currently receives $543 a month in survivor benefits, disqualifying her for welfare. No welfare means no Medicaid.

She is taking the experimental drug AZT and is supposed to have her blood tested every two weeks, but she can't afford it.

For now, Marilyn says, "I just take each day as it comes. If you start looking at too many things you get too depressed. It's rough. It's a hard thing to live with.

"I'm kind of stuck in limbo. People need to realize the AIDS epidemic is no longer just a gay thing, it's a family thing. And they need to realize there are going to be a lot more situations like mine."

For Peter, a 29-year-old homosexual from Essex County, having AIDS means having to live a lie.

"People see I got skinny so I tell them I have cancer. I told my nephew I have cancer. If he learns about AIDS in school he'll wonder, `Is my uncle gay or is my uncle a drug user?' I don't want my nephew to find out I'm gay.

"I know it's not nice to lie, but sometimes you have to lie to survive in this world," Peter says.

"You have to keep your mouth shut because there are so many people who don't care. My mother and father have a bakery. I have to keep my mouth shut and stay away from the bakery. People think if I work in there they can get AIDS and then they won't go to the bakery any more."

Peter was diagnosed with AIDS in May 1989 after three years of experiencing extreme fatigue and unexplained pain all over his body. "It took three years back and forth to doctors before . . .I finally insisted on going for the test.

"I've seen the change in myself and I'm very depressed. I went from 145 to 110 pounds. I look at myself in the mirror and I see my bones popping out. I look like a monster to me," says Peter, who recently was hospitalized with meningitis.

"I can't stand needles. I never took drugs. I had two lovers. One of them has it. The other, he doesn't really want to admit it but I can see he has it because he looks like me."

He is being cared for by his parents, both of whom are in their late 50s, and he feels bad about that. "My parents are tired and sometimes I feel I'm creating problems for them. They don't complain to me but I can see in their faces."

Peter hasn't worked in four years. He spends his time painting, drawing, watching TV and praying. "My life has changed so much. I go to church now. I feel much closer to God than ever before. And I hope He's going to come and pick me up soon because I can't take the pain any more. It's time for me to go."

NEW JERSEY: A STATE ORGANIZING TO FIGHT AIDS

A PLAN FOR THE 1990'S

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THE COMMISSIONER'S MESSAGE

THE FIRST CONFIRMED CASE of AIDS in New Jersey was diagnosed (retrospectively) in 1980. Since then, the state's public health officials have done much to combat this terrible epidemic. So have hundreds of dedicated individuals--including people with HIV infection and AIDS--working through dozens of community-based organizations and volunteer groups.

Nevertheless, as we enter the epidemic's second decade, we are confronting some bleak realities. In November 1990, the 10,000th case of AIDS was confirmed in New Jersey. As many as 40,000 to 50,000 more state residents are infected with HIV and, absent of a cure, virtually all of them will contract AIDS. Public awareness campaigns have been effective in reaching certain segments of the state's at-risk population, but not others. Almost 60 percent of New Jersey's people with AIDS are intravenous drug users, and this is not a segment of the population that has traditionally had much contact with the health care system, or has been particularly receptive to public health prevention and education efforts.

HIV infection and AIDS also strike our state's minorities and women particularly severely. This epidemic has only served to heighten our awareness of how difficult it is for many of New Jersey's citizens to effectively access our health care system.

In short, the end of this epidemic is not in sight.

We cannot wait for a "magic bullet" to beat AIDS. An effective vaccine is at least several years away, and no easy "cure" is likely, either. Consequently, we must act in concert, we must act vigorously, and we must act ***now***--and on several fronts concurrently--or our health care system, already frail and stretched to the limit, threatens to be overwhelmed by this epidemic.

We must do four basic things. We must identify those who are infected. We must slow the spread of the epidemic. We must deliver care and treatment services to people with HIV infection and AIDS. And we must evaluate our programs and determine which are working best and that our dollars are being spent well. This is particularly crucial in a time of fiscal constraint.

The foundation for these activities is already in place. In New Jersey we have a division within the Department of Health that devotes extensive resources to the battle against HIV/AIDS. But if one clear message emerged from the public meetings held around the state in conjunction with the development of this plan, it is that New Jersey's current HIV/AIDS effort has

been disjointed and disorganized. Education and prevention programs often miss their mark because they are not precisely focused or culturally appropriate. Services may be lacking in one geographic area and redundant in others. People are sick, suffering and dying and, too often, the system is not helping them as well as it should. At times, it is even getting in their way.

So, we need to do more, we need to do it soon, and we need to do it better. And, with the implementation of this plan, we will more effectively coordinate what we are doing; we will seek to integrate a variety of services to make each more focused and potent; we will endeavor to ensure that every dollar spent will achieve maximum intended result.

The plan that follows was developed by the concerted efforts of the Department of Health, the commissioners and staff of every department of state government involved with, or touched by, the HIV/AIDS epidemic, and a committee of concerned and knowledgeable New Jersey citizens.

This cooperation must continue as we move to implement this plan which Governor Florio requested 100 days ago. The plan offers recommendations, goals, and specific strategies to achieve them. Among the most important:

- Because the current HIV/AIDS service delivery system is uncoordinated and essentially unplanned, a network of **AIDS Resource Centers** will be established. The goal of these centers will be to develop a statewide service delivery system that is consistent from region to region. Each center will provide a comprehensive array of services through community-based resource coordination and case management. As soon as possible, we will fund three to five centers as pilot demonstration projects. If they succeed, as we anticipate, we will create over the next few years a network of 16 of these centers throughout the state.

- Because we believe that education is the single best weapon we have in our prevention arsenal, we will create and implement a **targeted prevention and education campaign** that reaches the general public and special populations in a culturally sensitive manner. A key component of this campaign will be the establishment of a **People with HIV/AIDS Speakers Bureau,** because no one can talk about AIDS as well as those stricken by it. Their messages will be eloquent and cautionary.

- Because New Jersey's fastest-growing population of HIV-infected persons is women of childbearing age, the Department of Health will create an **Office of Women and AIDS** within the Division of AIDS Prevention and Control. This office will be instrumental in

planning and implementing programs intended to impact on women and their children. Its first assignment will be to collect data to persuade the Centers for Disease Control to change its AIDS case definition, which does not take into account many female-specific signs and symptoms which are manifestations of HIV infection.

- Because resources for HIV/AIDS-related programs and services have not always been efficaciously allocated, we will put in place **evaluation and accountability mechanisms** so that we can determine which of our activities are successful and cost effective. This will be invaluable in the future as we plan and budget for HIV/AIDS activities.

- Because the input of those in the broader community who are knowledgeable about HIV/AIDS is invaluable, a permanent **AIDS Advisory Council** will be created to continue the planning process initiated 100 days ago. This council will report directly to the Commissioner of Health.

- Finally, because our efforts cannot exist in a vacuum, we will endeavor to encourage **public-private collaboration** that will result in an active, ongoing relationship between the state, private entities (e.g., universities, corporations, research institutions), and service provider groups (e.g., hospitals, community-based organizations).

The continued spread of the HIV/AIDS epidemic in New Jersey means that we will need to intensify our efforts to counter it. When implemented, this statewide plan will enable us to accomplish this comprehensively and cost effectively. Given the magnitude of the emergency before us, anything less would be unacceptable.

RECOMMENDATIONS

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IMPROVING OUR ABILITY TO IDENTIFY THOSE WHO ARE INFECTED

Researchers tell us that we are still some time away from either a cure or a vaccine for HIV/AIDS. Nevertheless, through early intervention we are making significant progress in helping people with HIV infection or AIDS--in delaying the onset of their symptoms, in mitigating the severity of those symptoms, and in improving the quality of their lives.

In order to effectively treat these people, however, we must know more about the extent of the epidemic. We must know who is infected, who is at high risk of infection, and how the disease manifests itself in those who are infected. Knowledge is an essential weapon in our fight against HIV/AIDS; increasing that knowledge is therefore an integral element in this HIV/AIDS plan for New Jersey.

We can do this primarily by HIV testing and reporting, and by seroprevalence testing to track the course of the disease and to determine its incidence and progression in distinct groups of the population. Secondarily, we must develop additional knowledge through research about more effective methods of education, prevention, treatment and service delivery.

ISSUE: **ASSESSMENT OF HIV IN NEW JERSEY**

BACKGROUND/DISCUSSION:

> ***"No one honestly knows down here in Southern New Jersey what the HIV seroprevalence is. My own impression is that there's a large pool of HIV-infected patients here in Southern New Jersey that nobody knows about."***
>
> *--Dr. David Condoluci*
> *Southern New Jersey TAP Program*
> *Camden Public Meeting*

The primary means of investigating the extent of HIV infection in New Jersey have been HIV seroprevalence studies of different populations. Blinded seroprevalence is testing performed after the removal of personal identifiers on blood samples drawn for other purposes. The fundamental difficulty with such surveys lies in applying the results from the specific population studied to the general population. Also there is little information on the incidence of HIV infections (the number of new infections) in New Jersey.

Blinded HIV seroprevalence studies are needed for certain populations not yet surveyed. These include inmates in state prisons and county jails, and individuals in both inpatient and outpatient settings.

RECOMMENDATIONS:

- **Blinded seroprevalence studies, including those funded by CDC, should be expanded to include populations not yet surveyed in order to obtain data which reflects true seroprevalence in these populations. In addition, evaluation of our prevention efforts requires some investigation of the incidence of HIV infection in New Jersey.**
- **It is essential that HIV seroprevalence surveys continue in New Jersey. It can be anticipated that the seroprevalence studies funded by CDC will continue over the next two years. These surveys should continue after the end of the current project period, even if state funds are required.**

IMPLEMENTATION STRATEGIES:

- The Department of Health should work with the appropriate authorities to initiate blinded seroprevalence testing for persons entering correctional facilities and for patients served by both clinics and hospitals.

- The department will continue its efforts to obtain additional funds from CDC for special projects. However, it may be noted that even federally-funded projects require some expenditure of state resources. The benefits to be derived from such projects in additional surveillance capacity are well worth the expenditure of additional state revenues.

ISSUE: **HIV REPORTING**

BACKGROUND/DISCUSSION:

> ***"It's my understanding that 35 percent of the patients who come to us for an HIV test do not return for the test results and the counseling that they need."***
>
> *--Robert Maher*
> *St. Michael's Medical Center*
> *Newark Public Meeting*

As the use of effective early therapy for HIV infection has progressed, a system of HIV reporting is becoming necessary. Patient assessment and tracking (surveillance) are fundamental to the control and prevention of disease.

Reporting of HIV infection with patient identifiers is currently required by law. Unless there is a change in the law, the Department of Health will have to require such reporting.

Concerns have been expressed that if reported information related to HIV-infected individuals is used or released improperly, discriminatory activities against such individuals could occur. In addition, the fear of such improper use of reported information might also diminish the willingness of people to be tested for HIV infection, which could be an impediment to appropiate care.

However, HIV infection reporting with identifiers will mean that better data can be obtained, as completeness of reporting and elimination of duplication can be much more readily assured. Of greater importance, knowing who the HIV-infected individuals are will allow the Department of Health to better assist in providing needed medical and other services for many HIV-infected persons. Many individuals with HIV infection do not have easy access to such services, and can be helped through assistance mediated by the Health Department. Resources will be needed to implement the mechanism of reporting and the complementary activities of partner notification, case management, and the provision of medical and other services to HIV-infected people.

RECOMMENDATION:

- **The Department of Health should, as required by law, pursue a policy of HIV reporting with identifiers, *under the strictest level of confidentiality,* in order to reach those who are infected and to offer them early intervention and case management services.**

IMPLEMENTATION STRATEGIES:

- All HIV reporting regulations will be brought into conformity with the current law.

- The enforcement of HIV/AIDS confidentiality legislation should be strengthened by imposing more severe penalties for breaches of confidentiality.

- Confidentiality procedures will be reviewed by the Department of Health in consultation with the Attorney General to ensure that information concerning HIV infection is not released except as necessary for public health purposes.

ISSUE: **CDC CASE DEFINITION OF AIDS**

BACKGROUND/DISCUSSION:

AIDS describes a severe, life-threatening disease which develops generally after several years of infection with HIV. The AIDS case definition, however, does not include all serious consequences of HIV-infection. New Jersey and New York, with higher proportions of HIV-infected women, children, substance abusers and minority populations, have reported a higher frequency of HIV disease beyond the current CDC case definition.

> ***"Because the CDC has a male model of the disease, many doctors do not test for HIV infection in their female patients. Early intervention can extend an AIDS patient's life. Right now the average life expectancy for all men with AIDS is two years from the day of diagnosis. It is approximately four months for women."***
>
> *--Katherine Neill*
> *ACT UP/Central Jersey*
> *Trenton Public Meeting*

The CDC AIDS definition is being inappropriately used by the Social Security Administration to deny entitlement benefits to these populations.

RECOMMENDATIONS:

- **New Jersey should begin to collect information on other illnesses that affect persons with HIV infection, which the CDC does not now include in its case definition.**
- **The CDC case definition for AIDS should not be used as the sole clinical basis for entitlement to Medicare.**

IMPLEMENTATION STRATEGIES:

- Special studies cataloging the clinical experience of women with HIV infection should be conducted in New Jersey to document the unique clinical syndrome of AIDS. New Jersey is in a better position than most states to contribute to this important effort.
- The appropriate state authority should petition the CDC to change its AIDS case definition to accurately reflect AIDS syndrome in women and other populations. The Social Security Administration should also be petitioned to cease using the current definition above to determine eligibility for benefits.
- Federal and state funds should be sought to investigate hospital clinic records to more accurately describe the course of HIV infection in these populations.

ISSUE: **HIV/AIDS RESEARCH**

BACKGROUND/DISCUSSION:

HIV/AIDS research serves many purposes. The most basic of these, of course, is to increase our knowledge of the disease so that more effective prevention and treatment methods and new medications can be developed and dispensed. Without research, prevention and control and care and treatment measures stagnate. It is essential that any HIV/AIDS plan for the state contain a research component.

> ***"We need to make sure that New Jersey is in the forefront of research of experimental drugs, both for HIV infection as well as the opportunistic infections."***
>
> *---Bill, PWA*
> *Camden Public Meeting*

HIV/AIDS research in New Jersey is conducted by a variety of institutions, including the Department of Health, the University of Medicine and Dentistry of New Jersey, Rutgers University, other institutions of higher learning, the pharmaceutical industry, hospitals and other health care facilities, and independent entities such as the New Jersey Community Research Initiative.

Most of the support for HIV/AIDS research in New Jersey comes from the federal government and from private sources. Given the high incidence of HIV/AIDS in New Jersey, the state does not conduct significantly large amounts of research in this vital area.

RECOMMENDATION:

- **The state should consider allocating a moderate amount of additional funds to complement the federal monies dedicated to HIV/AIDS epidemiological, behavioral, and clinical research.**

IMPLEMENTATION STRATEGIES:

- In the field of epidemiological research, studies on HIV-related mortality, heterosexual transmission of HIV, and HIV transmission in high-risk populations should be considered.

- In the area of behavioral research, the state should consider collaborating with academic institutions and relevant organizations and agencies on knowledge, attitudes, and behavior studies of the general population and of populations at high risk of infection.

- In the field of clinical research, the state should consider a study determining the natural history of HIV/AIDS in selected "special" populations.

- The state should consider increasing its participation in the Community Research Initiative, which conducts clinical trials on HIV/AIDS-related drugs.

SLOWING THE SPREAD OF HIV/AIDS

HIV/AIDS is a preventable disease. And education remains our single best weapon for preventing HIV infection and slowing the spread of the epidemic. In New Jersey and nationally, public awareness campaigns have proved effective in changing the risky behavior of gay men. But New Jersey's epidemic is unusual in that it is more concentrated among IV-drug users, their sexual partners and, increasingly, the children of HIV-infected mothers. The effectiveness of public awareness campaigns has not yet been sufficiently demonstrated in these groups, among others.

This makes it even more imperative that we renew our education efforts, not only for the general public, but for those groups who are disproportionately affected by the epidemic. The key to changing attitudes and behaviors is the provision of factual, consistent, and understandable information about HIV/AIDS by persons and organizations in whom the recipient has confidence.

Public awareness campaigns, therefore, can and should spring from many sources: community-based organizations, schools, churches, professional groups, and government at all levels--all with the assistance of people with AIDS. The Department of Health, should--and will--take the lead in mounting a multi-faceted, highly visible, culturally sensitive and carefully targeted public education campaign.

We can, and must, "get the word out" on HIV/AIDS to ***all*** New Jerseyans.

ISSUE: **COUNSELING, TESTING AND PARTNER NOTIFICATION**

BACKGROUND/DISCUSSION:

> ***"I do HIV antibody counseling and testing. I tell people that they've tested HIV-positive, and then I look at their faces and I see the fear, the shock, the devastation."***
>
> *--Carol Degraw*
> *Paterson Division of Health*
> *Camden Public Meeting*

Because of the unfortunate climate of fear and discrimination surrounding the HIV/AIDS epidemic, there is considerable controversy about the "best" mode of testing for HIV infection. From a public health standpoint, confidential testing is advantageous, since it yields more information about the extent of the epidemic, and facilitates early treatment intervention. No individual should be tested for HIV, however, unless he/she fully understands the difference between confidential and anonymous testing, and that both of them are available in New Jersey.

As more people become aware of HIV/AIDS, the demand for state supported counseling, testing and voluntary partner notification services will increase. Counseling and testing services have already been expanded beyond state-supported stand-alone CTS sites to include various clinics e.g., STDs, prenatal, drug and others. The objective is to integrate HIV counseling and testing as a component of all services delivered in those clinics. This would mandate a shifting of resources; greater utilization of test sites will necessitate a corresponding commitment of resources to serve increased numbers. Of course, client confidentiality procedures must be ensured.

Greater utilization of testing/counseling services will require better training and knowledge on the part of counselors to deal compassionately and effectively with all segments of our population. Continued training of these counselors is needed to ensure the best possible service.

Voluntary partner notification is an important component of these services. The demand for partner notification services currently exceeds our ability to respond. In New Jersey, notification assistance intervention has been demonstrated to be effective. Over 80 percent of those contacted had not recognized their risk behavior and would not have otherwise considered testing.

RECOMMENDATIONS:

- **The Department of Health should encourage confidential testing and reporting of HIV with informed consent while preserving and providing the option of anonymous testing for those who seek it.**
- **The Department of Health should expand the availability of HIV counseling, testing and voluntary partner notification activities throughout the state.**
- **The Department of Health should develop and implement a formalized HIV counselor certification program to maintain the consistency and accuracy of pre- and post-test counseling messages.**

IMPLEMENTATION STRATEGIES:

- The Department of Health should actively pursue a policy that expands the availability of confidential testing, while making available anonymous testing to those who desire it.
- Counseling, testing and partner notification services should be expanded to serve more clients at family planning and prenatal clinics, drug treatment clinics, sexually transmitted disease clinics, community health centers, and local health departments.
- The State Legislature should enact laws which ensure that informed consent is obtained prior to confidential testing. The department will support such legislation.
- The Department of Health should establish an HIV Counselor Certification Program.
- The department should encourage ***all*** hospitals in the state, particularly those in high prevalence areas, to establish voluntary HIV counseling and testing for all hospital admissions with informed consent.

ISSUE: CONDOMS

BACKGROUND/DISCUSSION:

HIV/AIDS is both a blood-borne and a sexually transmitted disease. Intervention with a goal of interrupting both methods of transmission is important if we are to diminish the incidence of HIV infection.

> ***"I go down there and I tell these guys to use condoms, to use bleach kits, but I can't give them to them. I would like to see something done about that."***
>
> *--Robert McEntire*
> *Paterson Division of Health*
> *Camden Public Meeting*

The most effective methods of prevention of the sexual transmission of HIV are abstinence from penetrating sexual activity and monogamous sexual activity between HIV-negative couples. Educational prevention efforts should be directed toward promotion of such behavior.

However, many people, including IVDUs and HIV-positive persons, do not follow these recommendations. Studies have shown that while proper use of condoms does not completely eliminate the risk of HIV transmission, it does greatly diminish that risk. The regular and correct use of condoms, especially by at-risk populations, can help decrease the spread of HIV infection.

RECOMMENDATIONS:

- **The Department of Health and other service providers that interact with at-risk groups should incorporate into their educational and outreach activities information about the proper use of condoms for those who are neither abstinent nor monogamous with an HIV-negative partner. Such prevention activities should continue to stress the importance of abstinence and monogamous behavior between partners.**
- **Condoms should continue to be distributed by public agencies in support of this activity.**

IMPLEMENTATION STRATEGIES:

- Educational materials should be developed which properly describe the use of condoms to diminish the sexual transmission of HIV. Such material should include instruction on the proper use of condoms.
- State as well as federal funding should be among the resources available to provide educational material about condoms, as well as for the purchase and distribution of condoms to support these educational activities.

ISSUE: **NEEDLE/SYRINGE EXCHANGE**

BACKGROUND/DISCUSSION:

After considerable discussion, the Community Advisory Committee recommended that a needle/syringe demonstration project be included as part of this state HIV/AIDS plan. However, there is no compelling epidemiologic evidence that needle/ syringe exchange programs have decreased the rate of HIV transmission among drug users.

Needle/syringe exchange programs are not without cost, and would use resources that could otherwise go to enhance drug treatment. In addition, needle/syringe exchange programs send the wrong message to those who need help most by condoning behavior that, incontrovertibly, has destructive effects on both the human body and spirit.

It is the position of the Department of Health that the evidence currently availlable does not warrant introduction of a needle/syringe exchange program. Good public health policy dictates that efforts be directed toward elimination of the use of addictive substances through programs that stress prevention and treatment. The department will continue to examine and evaluate various methodologies to diminish the transmission of HIV as it affects illicit drug users and their contacts.

ISSUE: **EDUCATION AND PREVENTION OF HIV/AIDS IN SPECIAL POPULATIONS**

BACKGROUND/DISCUSSION:

Anyone can get AIDS. The epidemic in New Jersey, however, has struck certain populations much more heavily than others. A public awareness campaign that is effective for one group may not be for another. In planning such a campaign--or campaigns--particular care must be taken to ensure that the messages are "right" for the audience.

> ***"The important message that we must stress is that the risk of AIDS is not about who you are or where you are. The risk is about what you do. It doesn't matter if you're white or black, rich or poor, young or old or Jewish or Catholic or Muslim. It doesn't matter. The virus is amoral."***
>
> *--John Dubois*
> *South Jersey*
> *AIDS Alliance*
> *Camden Public Meeting*

The campaign should of course address the general public. But major elements should also be targeted to spread populations affected by the epidemic, to include:

- **substance abusers**
- **women**
- **minority groups**
- **incarcerated persons**
- **gays and bisexuals**
- **youths, adolescents, and young adults**
- **the disabled**
- **the older population**

GENERAL RECOMMENDATIONS:

- **The Department of Health should develop and implement an innovative, comprehensive, highly visible, and multi-faceted HIV/AIDS public awareness campaign. Its object will be to reduce the spread of HIV infection by increasing the public's knowledge of HIV/AIDS generally, and of risk behaviors and modes of transmission in particular.**

- **This campaign will be facilitated by the establishment of a "People with AIDS Speakers Bureau." This planning process has taught us that people with AIDS can tell the story of this epidemic as no one else can, and they bear witness to the fact that it is possible to *live* with AIDS--and live productively.**

IMPLEMENTATION STRATEGIES:

- The Department of Health in conjunction with the Department of Labor will work more closely with New Jersey business and local governments to educate and inform their employees--via pay check, telephone bill and/or utility bill inserts--about HIV/AIDS-related issues.

- The state should begin to plan and then implement a "People with AIDS Speakers Bureau."

- Public assistance programs such as the state's welfare program will be utilized to serve as a valuable vehicle to disseminate educational materials to special populations that may be at risk of HIV infection.

- Although it addresses the general public, this campaign will also be targeted to the following special populations:

Substance Abusers

(For the purposes of this plan, substance abuse is broadly defined to include heroin, cocaine, crack cocaine, other addictive drugs, and alcohol.)

> ***"People are willing to change their behavior if they're given the information in the manner that is usable and told in a way that is doable, that you are somebody, and that you do count, and that you can win."***
>
> *--Joe, a recovering addict*
> *Camden Public Meeting*

The New Jersey HIV/AIDS epidemic is unique in the nation because nearly 60 percent of its 10,000 cumulative AIDS cases are related to intravenous drug use; this is, therefore, the state's primary mode of HIV transmission. Of the estimated 50,000 regular intravenous drug users (IVDUs) in the state (at least twice that number are occasional heroin users), approximately 6,000 are currently in treatment. An estimated 50 percent of IVDUs in the state's larger cities, including Newark and Jersey City, are HIV-infected. A majority of the 31,217 adults incarcerated in New Jersey's correctional system are IVDUs, and HIV/AIDS has hit this particular population very hard.

Poverty, discrimination and rootlessness make drug users one of the most difficult populations to reach. Most IVDUs are heterosexual and sexually active; their sexual partners, many of whom are women of childbearing age, are also at risk. Nationally, 49 percent of women with AIDS have contracted it through heterosexual transmission; most of the children with AIDS in New Jersey become infected, directly or indirectly, through a drug-using parent. It should also be noted that in New Jersey minority women are disproportionately represented among women with HIV/AIDS.

Since 1982, New Jersey has consistently had more than twice the percentage of female AIDS cases when compared to the United States. This is attributable to female transmission via intravenous drug abuse, which accounts for 1,295 cases and is 64 percent of adult/adolescent female cases and to women contracting the virus from their male sexual IV drug-abusing partners (602 cases, or 30 percent of all female cases).

Effective drug treatment in New Jersey is synonymous with AIDS prevention. Moreover, the total cost of drug treatment is significantly less than the cost of AIDS care. Outpatient methadone treatment, for example, costs between $2,200 and $3,000 per year. The costs of residential treatment range from $14,000 to $20,000 per year. On the other hand, the average lifetime cost of treating a person with AIDS has been estimated at $75,000.

Despite these financial realities, the quality and quantity of drug treatment available in urban areas of the state is inadequate to meet current needs. In fact, since 1981, New Jersey's drug treatment facilities have been forced to charge fees due to cutbacks in funding. This has been an additional deterrent to users seeking treatment. The state's capacity to identify, assess and treat substance abusers must be increased.

Any education and prevention program for substance abusers should treat, rehabilitate and educate both them and their sexual partners, and inform them about and encourage them to seek appropriate testing and counseling services. The department must work to expand the capacity of existing drug treatment clinics to serve those who seek treatment, and should continue to provide education and information on HIV/AIDS to counselors and medical staffs of drug treatment centers to enhance their ability to educate and counsel drug abusers on reducing their risky behavior.

RECOMMENDATIONS:

- **Since effective substance abuse treatment in New Jersey *is* HIV/AIDS prevention, it should be implemented as part of the HIV/AIDS care and services continuum.**
- **Substance abuse treatment--both inpatient and outpatient--should be available on demand.**
- **Legislation should be enacted to ensure that the full range of drug treatment is available for all who require these services.**
- **The state should create a substance abuse program designed to meet the often unique educational, prevention and treatment needs of minority women, and of pregnant drug abusers.**

IMPLEMENTATION STRATEGIES:

- The state should initiate a needs assessment for the number and types of drug treatment slots needed, pursue avenues for adding spaces and finding the funding to pay for this.

- HIV testing, counseling, and early intervention should be made available onsite to all methadone patients.

- Programs specific to women should be established in seven methadone and three residential drug treatment programs. These programs should provide culturally sensitive educational and therapeutic intervention and medical referral.

- Substance abuse programs should be integrated into such existing facilities as hospitals and community health centers.

- All programs in the Department of Health serving high-risk families and individuals (e.g. tuberculosis, STD, family planning, prenatal and maternal and infant health) should have a substance abuse/HIV specialist on staff to provide staff education, patient consultation, assessment and referral. There should be cross-training of staff.

- The state should review existing sources of funding (e.g. local general-assistance programs, Medicaid, private insurance plans) for coverage of drug treatment services or expansion of existing coverage.

- The state should fund expanded substance abuse services for pregnant women in residential facilities, and increased outreach for women and adolescents.

- The state will continue to educate drug abusers in methods of preventing HIV transmission, such as using bleach to clean needles and "works."

- The state will continue to educate drug abusers in methods to prevent sexual transmission of HIV.

Women

> ***"If we abrogate our responsibilities as far as educating women and the developing child, then we're doomed."***
>
> *--Steven Marcus*
> *NJ Poison Information and Education System*
> *New Brunswick Public Meeting*

The fastest rate of growth of HIV/AIDS cases is among women and infants. The majority of these women are not aware that they are infected.

In 1989, "Generations in Jeopardy" described the impact of the HIV/AIDS epidemic on women, children and adolescents. That same year, the Department of Health's second statewide HIV Maternal/Neonatal serosurvey was completed. This blinded survey represented a 100 percent sampling of all the newborns for a three-month period. The results indicate a statewide prevalence of 0.52 percent, or approximately 600 HIV-positive births per year. This prevalence reflects very closely the serosurvey conducted in 1988 which yielded a statewide prevalence of 0.49 percent.

HIV-positive births have occurred in virtually every New Jersey county over the two-year period during which the study was conducted. The dramatically increasing number of HIV-infected women and children indicate that the implications of this data warrant immediate attention by all practitioners.

Many minority women do not feel that they are in control of their own lives. The burdens of poverty, broken families, infant mortality, hunger and drug abuse make it difficult, if not impossible, for some women simply to get from one day to the next. The advent of AIDS, so often intertwined with drug abuse and other problems, has simply increased the burden. Steps must be taken to empower minority women and, in particular, to help them develop knowledge and skills which can enable them to confront and resolve problems related to health care and treatment.

> ***"I feel that a lot of women that I know are in dying need of help. We need a lot of education, a lot."***
>
> *--Michelle, PWA*
> *Newark Public Meeting*

Well-conceived and culturally sensitive education and prevention programs must be developed to reach these women. The efforts should focus on women of childbearing age who are HIV positive; women who are IVDUs or who are sexual partners of IVDUs; women whose sex partners are bisexual; and sexually active women with multiple partners. Education and prevention programs must be community-based, and must reach out to places where women congregate: clinics, laundromats, day care centers and schools, and churches. Education and prevention messages must contain information on safer-sex techniques, the risks of needle sharing, and perinatal transmission of the disease; they also should assist HIV-infected women in obtaining family planning services. All efforts to prevent the spread of HIV/AIDS in women should be culturally sensitive and should address the need for women to assume control over their bodies, their health, and their lives.

RECOMMENDATIONS:

- **The state should ensure that education and prevention activities for women are coordinated at the state level.**
- **The Department of Health should set standards that ensure that prenatal care programs, physicians, and community clinics provide pregnant women with counseling on HIV infection (including the risks for HIV infection, and the existing options regarding the availability of early medical care for women and infants) and offer voluntary HIV antibody testing.**

IMPLEMENTATION STRATEGIES:

- The Departments of Community Affairs and Health should coordinate their efforts to address women's issues, which must include prevention and education.
- The Department of Health, should plan, coordinate, and consult with perinatal centers, family planning clinics, physicians, community clinics and Treatment Assessment Programs to ensure that prevention and education is provided to pregnant women.
- The Division of AIDS Prevention and Control should establish an Office for Women and AIDS, which will have prime responsibility for addressing prevention and education issues, and any others related to women and the HIV/AIDS epidemic.

Minority Groups

Fully two-thirds of cases of AIDS in New Jersey occur in minority groups. Educational efforts for these groups must recognize differences in culture and language. Written materials and media messages should use appropriate language and should reflect cultural practices, beliefs, religious tenets, etc. Every effort will be made to get these messages out in the most appropriate media and timely manner.

As HIV/AIDS continues to spread particularly rapidly in New Jersey minority communities, it is becoming increasingly important that the state use minority-based community agencies that are familiar with, and culturally sensitive to, the individuals they serve.

Grant-funding methods must be evaluated and efforts increased to identify and fund less traditional, community-based health organizations, services and health-education strategies that are more appropriate to the communities they serve. Community-based centers generally are attractive because they can provide "one-stop shopping" for individuals with HIV/AIDS. Consideration should also be given to increasing funding to local health departments, since they often serve as primary providers to underserved populations. Grant-evaluation data should be analyzed to determine the actual impact that service delivery, education, and outreach are having on the HIV/AIDS epidemic in minority communities.

> ***"We have to teach our people in the same language that they understand, that they speak."***
>
> *--Julio Salinas*
> *Puerto Rican Association*
> *Trenton Public Meeting*

Outreach and education should also be increased in an effort to recruit and maintain a racially and culturally balanced professional staff, particularly in those programs which target high-risk minority communities. Available funds should be used to train and employ indigenous community health workers. These individuals can be very resourceful in capturing hard-to-reach clients in their communities.

Finally, coordination of services at all levels--intradepartmental and interdepartmental--is absolutely critical to addressing a major public health problem like AIDS. The state's efforts must be focused on developing a collaborative environment that encourages all providers to participate, and that eliminates the current overly fragmented system.

RECOMMENDATIONS:

- **The state should promote better coordination of, and access to, HIV/AIDS services, including prevention and education in high-risk minority communities.**
- **The state should insure that the service reflect the specific cultural and ethnic beliefs of target group.**

IMPLEMENTATION STRATEGIES:

- The Department of Health should increase its efforts to identify and fund community-based organizations providing HIV/AIDS services. A particular effort should be made to identify and fund less traditional community-based services and outreach strategies.
- The department should increase its efforts to recruit and maintain a racially and culturally balanced HIV/AIDS professional staff, particularly in those programs which target high-risk minority populations.
- Whenever possible, minority community health workers should be trained and employed. They can be particularly useful in finding and enrolling hard-to-reach clients.

Incarcerated Persons

The incidence of HIV/AIDS in the incarcerated population in New Jersey is among the highest in the United States. In New Jersey this problem, compounded by substance abuse, affects inmates, their families and communities. Inmates must rely on their custodians to provide all services. It is therefore imperative that the Department of Corrections, in conjunction with the Department of Health, establish policy and plans for an HIV/AIDS program for all inmates.

One of the key tasks in formulating such a program is determining whether or not the Department of Corrections can impose standards on local correctional facilities. A mechanism must be developed by the state that will create a uniform standard of HIV education, testing, counseling and care applicable to all inmates in the correctional system.

There is also growing concern in New Jersey over the lack of education provided to the spouses of inmates. There are few educational materials available and only marginal outreach is being provided. The New Jersey Association on Correction has a special outreach to women, which might be investigated as a model to expand HIV/AIDS efforts to women in general. This program supplies trained women to go out into the community and educate women either one-to-one or in groups.

RECOMMENDATIONS:

- **The Departments of Health and Corrections should jointly develop a standardized, coordinated HIV/AIDS educational program for all inmates.**
- **A non-coercive method should be developed to encourage high-risk individuals to test voluntarily. Pre- and post-test counseling should accompany testing and policies can be mandated to ensure confidentiality of test results. Outreach efforts to spouses of inmates, as an additional high-risk population, should also be expanded.**

IMPLEMENTATION STRATEGIES:

- The state should pursue resolution of questions concerning the Department of Corrections' authority over municipal and county jails, and initiate and continue dialogue to standardize testing, counseling and treatment of HIV-infected inmates at all facilities.
- The state should coordinate an educational program between the Departments of Corrections and Health to be given to all inmates upon admission and discharge.
- The state should coordinate efforts of the Departments of Health and Corrections to train and counsel inmates and their families in HIV awareness. A program to select, train and utilize inmates as certified HIV counselors could be implemented. This group of inmates could be used in educational programs for juveniles within the Corrections system, and their expertise could help prepare them for employment opportunities upon release.
- The Department of Health should work with the Department of Corrections to gain support for implementation of a voluntary testing and counseling policy for all state corrections inmates.

Gay and Bisexual Men and Women

At the present time, only a few AIDS programs in the state provide adequate prevention education specifically targeted to gay and bisexual men and lesbian and bisexual women. Most of these programs are in the northern part of New Jersey.

This may be attributable, at least in part, to New Jersey's distinction as the only state in which reported AIDS cases in IVDUs exceed those among gay and bisexual men, as well as to ignorance and fear of these men and of lesbian and bisexual women.

It has been assumed in some quarters that the incidence of AIDS in the gay population of the state is diminishing. This is not the case. In ten counties in the state, the primary mode of transmission of HIV continues to be unprotected sex between men. Although some successful prevention programs have been targeted to gay men and lesbians in the past, these programs now exist only as remnants, or are considerably less active. A certain segment of the population may have received the prevention message. But there is a growing number of younger people, including lesbian and gay adolescents, who remain uninformed. It is therefore imperative that efforts be directed toward gay and bisexual men and lesbians and bisexual women to ensure that the incidence of HIV infection and AIDS does not increase.

RECOMMENDATIONS:

- **The state should ensure that sufficient and effective educational and prevention programs are developed for gay and bisexual men and women.**
- **The state should identify and/or develop materials and strategies to assist service providers in offering information to gay and bisexual men and women.**

IMPLEMENTATION STRATEGIES:

- The Department of Health should issue a sufficient number of Requests for Proposals for prevention/education projects targeted to these populations in its next round of funding for community-based organizations.
- The state should encourage and work in concert with gay and lesbian organizations to expand their education efforts, such as the "buddy support system," which focus on risk reduction.
- The state should include, when appropriate, gay and bisexual men and lesbian and bisexual women in the target populations for all funded projects.
- The Division of AIDS will review HIV prevention materials currently distributed, as well as training programs sponsored by the division, in order to identify and/or develop materials and strategies which are most effective in providing prevention education to gay/bisexual men and lesbian/bisexual women.

Youths, Adolescents and Young Adults

HIV/AIDS is spreading among teenagers and young adults at an alarming rate. A recent study estimated that one of five hundred college students may be infected with the virus. The goal of educational efforts for this population should be to increase the awareness and understanding of school-and college-aged students about AIDS and risk behaviors.

> ***"We need more education--for your children and for my children. Because I'm not only worried about me, I worry about them. Who is going to sit on this panel tomorrow?"***
>
> *--Barry, PWA*
> *Newark Public Meeting*

The adolescent population is an especially difficult group to reach. At this age young men and women are awakening to the physical desires of their bodies and encountering the peer pressures of their friends. This is a challenging and critical time for adults to provide information to them about drugs and sex. If this is not done by their parents, institutions must assume the responsibility of informing these young people of the specific behaviors needed to avoid HIV infection. We need better programs to reach adolescents.

Street children and runaways pose a particular problem for social service agencies. The first instinct of these children is to avoid contact with any agency that may return them to their former home or situation. Non-threatening and non-intrusive services work best with these young people. It is not surprising that the institutions, facilities or agencies providing the best services for street children are those that have been established with a specific emphasis on the young. Services and facilities needed include: "walk-in" centers offering food, shelter and clothing; small, non-intimidating health care clinics located in areas where these young people congregate; emergency shelters; and residential care facilities for young people with HIV/AIDS.

On the streets the need to survive often leads to sex for money or the use of drugs. Services including prevention and education should particularly target adolescent substance abusers, young people with HIV/AIDS and other sexually transmitted diseases, and pregnant teens.

Since peer pressure is a major force in modifying adolescent behavior, a peer-education and behavior-modification program should be effective with this population.

The State Board of Education has mandated a coordinated sequential elementary and secondary curriculum in HIV prevention education with instructional units appropriate to the age, growth and development, and maturity of the pupils. HIV

instructional guides have been developed and distributed by the Department of Education. Instruction on HIV prevention is usually part of the family life educational and substance abuse prevention curricula. It may be taught at the junior high and high school levels by the school nurse, health education teacher or physical education teacher. Individual counseling may be done by substance awareness coordinators or guidance counselors. At the elementary level, family life is most commonly taught by the regular grade-level teachers.

Selection of appropriate curricula to comply with State Board of Education instructional mandates is the responsibility of local school districts.

The differentiation in authority limits the ability of the Department of Education to ensure the effectiveness of local school instruction in areas in which there is no standardized state testing program.

The Department of Higher Education handles the affairs of three public universities, nine state colleges, 24 independent degree-granting institutions, and 19 community colleges. The department also provides funds directly for several on-campus programs designed to support the academic development of students. These programs also address relevant areas of student personal development, which is the appropriate area for HIV awareness education.

RECOMMENDATIONS:

- **The state should implement programs to increase the quantity and quality of HIV prevention education at all grade levels for all school-age children in New Jersey.**
- **Education and prevention strategies and services should be expanded and/or developed for street children and runaways.**
- **Programs should be developed to reach adolescents, as a specific HIV/AIDS population with distinct needs.**
- **The state should strengthen provision of HIV-awareness education for all college students.**

IMPLEMENTATION STRATEGIES:

- The state should investigate methods of implementing and ensuring the content of HIV/AIDS prevention instruction taught at the local school level in accordance with the State Board of Education mandate and Department of Education instructional guides.

- The state should support the training of public and nonpublic school teachers in HIV/AIDS prevention education, utilizing Department of Education instructional guides.

- The state should support the training of substance awareness coordinators already in place at the secondary school level in HIV/AIDS prevention education; subsequently, guidance counselors, school nurses and school social workers should receive similar training.

> ***"It's up to the state, it's up to the local school districts. They can basically say, Don't get AIDS, just don't have sex and don't shoot up, and that is fullfilling the state's requirements. And that is a shame."***
>
> *--Daniel Pichinson*
> *High School Student*
> *Camden Public Meeting*

- The state should coordinate efforts between the Departments of Community Affairs, Health, Education and Human Services to provide training and technical assistance to community-based organizations and youth corps agencies that provide services to out-of-school youth.

- Street children and runaways are a particularly difficult population. The state should investigate development of peer education and behavior modifications programs, to be given at "walk-in" centers, small clinics, emergency shelters and residential care facilities where these young people congregate.

- For students enrolled in the state's institutions of higher education, the state should pursue dialogue on methods to directly involve college students in HIV/AIDS awareness initiatives, to support substance abuse/HIV program directors at the 29 public colleges, and to provide assistance and leadership to the 24 independent colleges by supporting professionals as consultants and "directors on loan."

- The state should investigate the possibility of supporting at least bi-annual anonymous behavioral surveys of college students on selected college campuses in New Jersey to evaluate the impact of HIV awareness programs.

ISSUE: DISABLED AND IMPAIRED POPULATIONS

BACKGROUND/DISCUSSION:

These populations include individuals with mental or developmental disabilities, with vision and hearing impairments, and other individuals with "special needs."

Discrimination against the mentally ill is not a new phenomenon, but the advent of AIDS--some of whose manifestations are neurological and psychological--has created yet another group that is encountering difficulties in accessing education, medical care and treatment.

In order to ameliorate this problem, appropriate HIV/AIDS education, developed by the Division of Mental Health and Hospitals of the Department of Human Services, is needed for both staff and patients in the state's public and private mental health facilities. "Special needs clients," as defined by the Division of Mental Health and Hospitals, should be integrated into the education process through policies developed jointly by the Department of Health's Division of AIDS Prevention and Control and the Division of Mental Health and Hospitals. Particular attention should be given to both client and operators of congregate living facilities.

Developmentally disabled persons and their families also need HIV/AIDS education by individuals familiar with this population. The curriculum for this education program could be developed as a joint venture between the Departments of Health and Human Services.

Persons with vision and hearing impairments must be considered in any education and prevention campaign.

RECOMMENDATIONS:

- **Developmentally disabled persons and other populations with special needs and their families should be educated about HIV/AIDS at the appropriate level by individuals familiar with these populations.**
- **Efforts must be made to ensure that visually and hearing impaired individuals receive HIV prevention and education messages.**

IMPLEMENTATION STRATEGIES:

- The state should investigate the feasibility of requiring the ongoing HIV/AIDS education of mental health services providers as a requirement for facility and professional licensure or certification.

- The state should initiate dialogue with administrations of facilities for mentally ill and developmentally disabled persons to improve the dissemination of educational material on HIV/AIDS and infection control at a level that the residents can understand; the state should monitor the compliance and the effectiveness of this material.

- The state should encourage all direct mental health service providers to include ongoing HIV/AIDS education.

- The state should coordinate its efforts between departments to ensure that materials on prevention and education are provided to visually and hearing impaired persons.

ISSUE: THE OLDER POPULATION

BACKGROUND/DISCUSSION:

There is a need to address the situation of older people who act as caretakers of persons infected with HIV, or who are themselves infected. This need will increase as more therapies are developed which prolong life.

In the public hearings, older caretakers testified about the difficulties of caring for younger HIV-infected family members, and their need for education and prevention information.

As yet, there is not enough clinical information on whether or not older people over 60 with HIV infection exhibit different manifestations than do younger people. This will have to be monitored.

RECOMMENDATION:

- **The state should improve its educational efforts for the older population, from an HIV prevention/education perspective and from a caretaker perspective.**

IMPLEMENTATION STRATEGIES:

- The state should encourage coordination between the Department of Health and the Division on Aging in the the Department of Community Affairs to develop and distribute educational materials and conduct, directly or indirectly, educational sessions geared to older population.

- The state should investigate coordination and dissemination of prevention and educational messages for the older population with community-based organizations, including church groups and senior citizens centers, and groups such as the American Association of Retired People (AARP).

ISSUE: **EDUCATION AND PREVENTION OF HIV/AIDS IN THE WORKPLACE**

BACKGROUND/DISCUSSION:

A significant number of New Jersey's workers--particularly health care workers, emergency medical services personnel, fire, police, and correctional officers--have the potential for exposure to HIV in the workplace. Employees and employers alike need to receive accurate information regarding the risks of and methods for preventing exposure.

> ***"All of us-- parents, children, spouses, friends, partners, co-workers, neighbors--are affected."***
>
> *--Terence Zealand*
> *AIDS Resource Foundation*
> *New Brunswick Public Meeting*

The Department of Health's, Division of Occupational and Environmental Health and the Department of Labor, given adequate resources, could establish a mechanism for providing AIDS information and support to the occupational groups listed above on a priority basis and to all major industries in the state.

RECOMMENDATION:

- **Education and prevention activities and policies in the workplace should address general education about the virus, potential workplace exposure and outside exposure to HIV/AIDS.**

IMPLEMENTATION STRATEGY:

- These education and prevention activities and policies should be targeted to the following groups:

All Employees

The state should coordinate and improve its prevention and education services to all New Jersey workers. It should create an AIDS Awareness Council of diverse membership to coordinate and plan policies and awareness programs on behalf of all New Jersey workers.

The state should also establish a district task force within the Department of Labor to assist private sector business in developing and implementing policies on HIV/AIDS, and to provide the private sector with training support. It should provide follow-up consultation and technical assistance to employer and employee groups which have received this educational information.

The state should ensure the necessary planning and coordination by the Departments of Insurance, Health, and Human Services, and by the State Legislature so that both the private and the public sector share the responsibility to provide health insurance for workers with HIV.

The Department of Health in cooperation with the Department of Labor should promulgate regulations incorporating the "Ten Principles for the Workplace," as developed by the Citizens Commission on AIDS for New York City and Northern New Jersey. This should be considered, where appropriate, to guide workplace response to this ultimately fatal disease. These principles are intended as a framework for all employees, unions, and other employee representatives and business organizations that share the responsibility of responding to AIDS.

Health Professionals and Facilities

The Department of Health should develop a mechanism for providing AIDS information to occupational groups on a priority basis, beginning with health care workers, emergency medical services personnel, fire, police and corrections officers.

> ***"I would make it part of training of physicians either for initial or continuing licensure to have appropriate coursework [in HIV/AIDS], or other educational experiences that would allow them to be more effective in this role."***
>
> *--Dr. Jerome Platt*
> *Division of Addiction Research*
> *UMDNJ*
> *Camden Public Meeting*

The department should also consider setting regulations requiring the employment of universal precautions in all licensed health care facilities and clinical laboratories, first aid, rescue and ambulance squads, law enforcement agencies, correctional facilities, fire departments, and funeral homes.

The Department of Health should take appropriate action to ensure that all physicians in the state receive basic HIV/AIDS education and prevention training. The department should also work with the University of Medicine and Dentistry of New Jersey (UMDNJ) to develop training externships for physicians who wish to become familiar with state-of-the-art HIV management.

State Employees

The state should improve the provision of prevention, education and testing services to its employees. This could be accomplished by funding the Division of Occupational and Environmental Health to distribute educational materials, providing seminars, consultation, and technical assistance to New Jersey public employees.

DELIVERING CARE AND TREATMENT SERVICES

The preceding section of this plan calls for a comprehensive prevention and education campaign to increase New Jerseyans' awareness of HIV/AIDS. But no prevention and education effort, no matter how comprehensive, well-intended or well-funded, can be 100 percent effective. In the absence of a vaccine--and most researchers believe an effective one is at least five years away--more New Jerseyans will be infected with HIV. Moreover, at least 30,000 of them and probably more--***already are*** infected with this deadly virus; most of them, if not all, will eventually become symptomatic and require medical care.

Until recently, HIV/AIDS medical treatment was totally defensive--a progressively losing battle against increasingly severe opportunistic infections, cancers, and other illnesses. Eventually -- inevitably -- treatment became palliative, an easing of pain and suffering until death came. In the last year and a half, however, physicians have been attacking HIV infection more aggressively, through early intervention--if possible even before the manifestation of symptoms--with such medications as AZT and aerosolized pentamidine.

The concept of early intervention was institutionalized in New Jersey in 1989, with the establishment of the Treatment Assessment Program. TAP has proved very successful, but only five centers are in operation and demand is growing. This plan calls for the expansion of the TAP program.

Perhaps even more importantly, it calls for the coordination of care and treatment services (and all other HIV/AIDS services) in new, regional Resource Centers. These centers, delivering services through county-based case managers, will make HIV/AIDS care more efficient and accessible. Moreover, as a result of this process, we will learn more about the unique treatment requirements of many of the special populations afflicted with HIV/AIDS.

Resource Centers, case management, early intervention: the interaction of these critical elements recommended in this plan will result in an HIV/AIDS service delivery system that is more responsive to people's needs and can serve as a model for the nation.

ISSUE: COORDINATION OF HIV/AIDS-RELATED SERVICES

BACKGROUND/DISCUSSION:

A broad array of public and private sector activities surround the HIV/AIDS epidemic, including care and treatment services, educational and awareness programs, and support services. But most have not been well coordinated and therefore not easily accessed by persons with HIV/AIDS. Planning and coordination of HIV services is critical in achieving the twin goals of improving access to services for HIV-positive individuals and improving the quality of those services.

> ***"We have a situation where people are receiving services from a number of agencies in communities. . . . No one is talking. We need to talk to each other."***
>
> *--Carol DeGraw*
> *Paterson Division of Health*
> *Camden Public Meeting*

The Department of Health, through its Division of AIDS , has attempted to provide planning and coordination of services on a statewide basis. Although these efforts have been successful, they have met only a fraction of the needs of the estimated 30,000 to 50,000 HIV-infected persons in New Jersey.

Statewide planning and coordination efforts often take a broad approach in designing and implementing programs. This approach, however, may not necessarily reflect local programs having resources and expertise, or the diverse populations that are HIV-infected in many parts of the state. Effective HIV/AIDS policy must attempt to balance the need to provide a uniform set of essential core services while allowing for diversity of services based on need.

During this period of limited final resources it is vital that we develop a system of care in all parts of the state that serves at least a minimum number of persons. By so doing we can plan for the optimal use of services. This approach provides the flexibility necessary to address the needs of a densely populated, well serviced part of the state while also attending to the more sparsely populated rural areas.

The concept of AIDS Resource Centers was first introduced by the New Jersey Hospital Association in March 1988. The development of these centers is considered by many to be an effective way to focus planning and coordination at a regional and/or local level to provide HIV-positive individuals and organizations better access to necessary services.

AIDS Resource Centers, while assuming responsibility for planning and coordination, need not directly deliver all of the services which are provided to HIV-positive persons. However, the Resource Centers should function as the focal point for a consortia of service providers, and are not intended to create new systems of care where existing systems are operating in an appropriate manner. The centers should build upon existing systems. The establishment of these centers may be considered a healthy move away from crisis health care delivery, to one which treats HIV infection as a chronic disease.

RECOMMENDATION:

- **The state should implement a regionally based system of Resource Centers to coordinate all HIV/AIDS-related services. This system, resting on community-based case management, should ensure that HIV-infected persons and people with AIDS receive promptly and efficiently the medical care, treatment and social support services they require.**

IMPLEMENTATION STRATEGIES:

- The Department of Health should establish three to five demonstration Resource Centers which build upon existing service consortia and systems of care. The development of these centers will extend over a three-year period. During subsequent fiscal years, additional centers should be developed.

- Resource Centers should be supported with funding to establish them as the locus of planning and coordination of ***all*** HIV/AIDS related services in the region.

ISSUE: **CORE HIV/AIDS SERVICES**

BACKGROUND/DISCUSSION:

Several core services are urgently needed by HIV/AIDS patients. These include case management, to help navigate the complex health and social service systems; early intervention programs, to ensure that HIV-infected individuals receive appropriate treatment and drug therapy; and dental and nutritional services.

> ***"Everyone should be cared for by someone who loves them. You're really lucky if the someone who loves you knows how to get through the system."***
>
> *--Friend of a PWA*
> *Camden Public Meeting*

RECOMMENDATION:

- **In order to meet the growing needs of the expanding HIV/AIDS population, core services must be made readily available and easily accessible to all people with HIV in the state.**

ACTION AGENDA:

- The following core services required by HIV/AIDS patients should be provided:

Case Management

The three committees involved in the development of this plan recognized the imperative to develop a workable case management system. Such a system is integral to the institution of new HIV/AIDS services as well as the linkage to existing services. An effective case management system should enable patients to better navigate the medical and social service bureaucracies. A basic model for such a system is the AIDS Community Care Assistance Program (ACCAP).

Accordingly, a community-based case management system for all persons with HIV/AIDS should be developed on a county-by-county basis, beginning with the counties of highest HIV incidence. It should eventually evolve into a coordinated program incorporating ACCAP. The system should link currently existing services with new programs as they develop, and must be flexible and adaptable to the needs of the patient. It must provide standard levels of service delivery and include a contractual method to ensure compliance with established standards. Reimbursement for this system should be shared by the state and counties.

Early Intervention

> ***"Last year the TAP program came into existence. So, I was able to tell [my clients] that there is some hope. And then shortly after, about a month after, I needed to tell them that they'd have to wait six weeks or eight weeks, and sometimes ten weeks for their first appointment."***
>
> *--Carol Degraw*
> *Paterson Division of Health*
> *Camden Public Meeting*

The Treatment Assessment Program (TAP), which provides early intervention care and other support services to both asymptomatic and symptomatic HIV-infected individuals, should be expanded to serve other geographic areas of the state. These services should be incorporated into both hospital and ambulatory-based care centers, including community health centers, family planning clinics and selected drug treatment programs. TAP services and HIV-related medications should be integrated into a formalized reimbursement system under the auspices of the Department of Health.

A mechanism should be developed for ongoing reimbursement of TAP costs at both in-hospital-based ambulatory care centers and non-hospital-based ambulatory care centers. The Department of Health can improve access to TAP by expanding the TAP sites currently in operation and by extending the TAP concept to existing community-based ambulatory care centers and/or group practice physicians' offices. Access to TAP services should take no longer than two to three weeks.

AIDS Drug Distribution Program (ADDP)

Early intervention in the treatment of HIV-infected persons requires accurate diagnosis and an acceptable treatment plan, including state-of-the-art medication such as AZT. Such medications are expensive and must be taken on a long-term basis. ADDP provides medications for the treatment of HIV infection and its associated illnesses on an outpatient basis. This has been inexpensive for the state to administer, with minimal paperwork for patients. In many cases it enables HIV-infected persons to continue their normal activities.

ADDP should therefore be continued and expanded, and the state should continue to seek federal funds to pay for it. New drugs such as DDI can be evaluated for inclusion in the program as quickly as possible, and other drugs that are now used in outpatient treatment of HIV infection, such as Acyclovir, Ketoconazole, and Bactrim, can also be considered for inclusion.

Dental Services

The lack of adequate dental services for both adults and children with HIV/AIDS has been and remains a major concern throughout New Jersey. Only a small number of

dentists are currently willing to treat these individuals. Dental services must be made more available to adults and children with HIV/AIDS.

Dental clinics and mobile van services should be established or based in strategic locations, and community-based dental services by local practitioners should be expanded. The Advanced Education in General Dentistry program (AEGD), which trains residents in dentistry, should also be expanded to treat these underserved populations.

Medicaid must continue to cover dental services, and reimburse for them at a reasonable rate, and insurers' provisions for reimbursement for dental services should be expedited.

Nutrition

Nutrition may be the most neglected area in the care and treatment of HIV/AIDS. Nutrition encompasses both food and nutritional supplements, for it should be recognized that many PWAs in New Jersey lack not only information about proper nutrition but, in too many cases, simply enough food.

> ***"The four food groups of HIV-identified individuals are hoagies, hot dogs and steak sandwiches from the corner store."***
>
> *--Barbara Ford*
> *AIDS Coordinator,*
> *City of Newark*
> *Newark Public Meeting*

Access to adequate food supplies and proper nutrition should therefore be stressed as an important means of maintaining the body strength and the immune systems of those with HIV/AIDS. Nutrition should be stressed in educational material for people with HIV/AIDS, and every patient should receive a consultation with a registered dietitian, nutritional support team, or other knowledgeable persons or groups. Dietary supplements, reimbursable by third-party payers, should be made available.

ISSUE: **COMMUNITY-BASED HIV/AIDS SUPPORT SERVICES**

BACKGROUND/DISCUSSION:

> ***"[The plan] needs to be family focused, and we need to have access to a broad range of community-based care services. We also need financial and manpower resources in order to carry out whatever plan you come up with."***
>
> *--Elaine Ehrlich*
> *National Association of*
> *Social Workers*
> *New Brunswick Public Meeting*

One of the reasons that the HIV/AIDS epidemic is so difficult to confront is because patients require not only the most sophisticated medical care and treatment, but an entire array of support services not only for themselves but often for their families as well. These include medical day care, home health services, transportation, volunteer assistance, hospice and respite care, and mental health care. These support services, which are critical to maintain HIV/AIDS clients in their homes or other community settings, can be easily accessed through the Resource Centers.

RECOMMENDATION:

- **Support services for HIV/AIDS patients must be improved, expanded, and better coordinated through the Resource Centers.**

IMPLEMENTATION STRATEGY:

- The following support services should be coordinated by the Resource Centers and delivered to HIV/AIDS patients:

> ***"Without medical day care I would not be here. Their help and their love have helped me try and deal and cope with this disease."***
>
> *--Julio, PWA*
> *Newark Public Meeting*

Medical Day Care

Medical day care centers deliver preventive, diagnostic, therapeutic and rehabilitation services under medical supervision to meet the needs of functionally impaired adult patients. The cost of medical day care is less than that of long-term care and offers many of the same services.

However, existing medical day care centers are generally designed and structured to meet the needs of a frail elderly population, and HIV/AIDS patients may require some services that are not available in most existing programs. Moreover, operators of medical day care programs for HIV/AIDS patients indicate that reimbursement may be inadequate to meet their special needs.

Medical day care should be expanded statewide to provide services appropriate to the special needs of HIV/AIDS patients. The state should expand hours of operation for medical day care beyond the current 7a.m.-7p.m. hours in order to meet the needs of clients. Medical care insurance reimbursement should be related to the services provided, and licensure requirements setting age limits should be eliminated, so that young children and their parents may be treated as a family unit.

HIV/AIDS patients often suffer severe psychiatric symptoms, including depression, organic brain disease, and dementia. Mental health services must be expanded to treat these conditions.

Home Health Services

Home health providers supply those services needed by HIV/AIDS patients which enable them to remain in their communities and with their families. These services are less costly than institutionalized care and contribute to a better overall quality of life for HIV/AIDS patients. However, there is a shortage of trained providers in the system. The state, therefore, should encourage the expansion of home health services for HIV/AIDS patients. The Department of Health should also work with appropriate agencies and educational institutions to increase the number of certified nurses aides and homemakers. The staffing problems can be relieved in part through the development of volunteer "buddy" systems associated with home health agencies. Standardized training requirements for those volunteers should be established. Home health care providers should receive HIV/AIDS education to reduce their anxiety about providing services to this population. Physician reimbursement should be established for home visits.

Current programs for the elderly and medically needy should be investigated as a foundation for expansion of services to HIV/AIDS patients. The cost of transportation for people with HIV/AIDS should be covered by Medicaid, Medicare, and/or third-party payers.

Volunteers

HIV/AIDS services that would benefit from the participation of volunteers include homemaking, hospice care, support groups, and "buddy" organizations. However, many potential volunteers are afraid of AIDS.

At present, the Department of Health does not utilize resources from the business community to augment the pool of available volunteers. The state should act to involve more volunteers in providing HIV/AIDS support services, and work to reduce volunteers' fear of HIV/AIDS patients. It should also call upon other public agencies and the business community to provide volunteers, and offer creative incentives to attract volunteers to work with underserved populations.

Transportation

> ***"We live in an area where public transportation is extremely limited. In cases where service is available, clients have no funds to access it and we have no funding to provide such access."***
>
> *--Bobbie Taylor-Foster*
> *Westside AIDS Project*
> *Camden Public Meeting*

Transportation for HIV/AIDS patients to care and treatment services in New Jersey is a problem when individuals must travel to and from services and physicians. Adequate transportation should be available to and from all organizations and facilities serving HIV/AIDS patients. All certificate of need or grant applications should address the issue of availability of transportation to services in the applicant's geographic area, and the development of any new program or clinic should take into account the availability and accessibility of public transport.

Hospice Care

> ***"Ours is a well established hospice program. We've done a lot of fundraising, but we're going to drown, too, unless we receive some help financially in caring for these patients. . .Lots of programs don't seek to work with people with AIDS because they know they're going to drown financially if they do."***
>
> *--Susan Fecko*
> *Project Outreach*
> *New Brunswick Public Meeting*

Hospice care is an approach to treatment which recognizes that the impending death of an individual warrants a change in focus from curative to palliative care. The goal of such care is to help terminally ill individuals continue to live as normally as possible while they remain primarily in a home environment.

Both home and institutional hospice care should be made more accessible and available to all New Jerseyans who would benefit from it such care. The availability of a caregiving family member or friend should not be a necessary eligibility requirement for home-based hospice services, nor should the six- to twelve-month life-expectancy limit be imposed as a condition for hospice care.

Respite Care

Opportunities for respite care should be expanded so that those individuals--especially maternal caregivers caring for their children, or even their children's children--can continue to do so. It should be kept in mind that volunteers can be a major source of respite care, if they are trained, tracked, and monitored carefully.

Mental Health Services

Many HIV/AIDS infected persons develop neurological and psychological problems in addition to their acute medical needs. This group of patients requires mental health services that can not only address the behavioral problems resulting from dementia and organic brain syndrome, while maintaining these clients in community-based settings. Appropriate training of mental health service providers is vital to help meet the needs of HIV/AIDS patients.

The Division of AIDS, in cooperation with the Division of Mental Health and Hospitals of the Department of Human Services, should develop appropriate HIV/AIDS education for both staff and patients in the state's public and private mental health facilities. "Special needs clients," as defined by the Division of Mental Health and Hospitals, should be integrated into the education process; policies to accomplish this should be developed jointly by the Department of Health's Division of AIDS Prevention and Control and the Division of Mental Health and Hospitals. Particular attention should be given to both clients and operators of congregate living facilities.

Better information-dissemination and service-planning mechanisms for mentally ill HIV/AIDS patients should also be developed.

ISSUE: **FACILITY-BASED HIV/AIDS SERVICES**

"I'm confronted by one inescapable and disturbing conclusion: we have failed our patients. Certainly, there have been heroic efforts by institutions and individuals in their treatment of AIDS patients. Extraordinary kindness and compassion is not uncommon. But as a system of regulators and providers, we have failed because we refuse to let go of what is most familiar, most comfortable--the acute care focus system of diagnosis and treatment--rather than embrace and empower the concept of continum care and all the diversity that that concept implies."

--Marc Lory
University Hospital UMDNJ
Newark
Newark Public Meeting

BACKGROUND/DISCUSSION:

Since the onset of the HIV/AIDS epidemic, the great majority of patients have been treated in the acute care hospital setting. This is expensive; it is not always necessary or even desirable. It has evolved because there is a serious shortage of subacute (alternative to acute care) services and housing for the HIV-infected and people with AIDS. As the focus for all HIV/AIDS treatment shifts to community-based care, there should be less of a demand for facility-based services.

RECOMMENDATION:

- **Where appropriate and when need is documented, the state should encourage expansion of subacute care facilities for people with HIV infection and AIDS.**

IMPLEMENTATION STRATEGY:

- The following subacute care settings should be utilized whenever possible for people with HIV/AIDS:

Residential Health Care

A residential health care facility furnishes food, shelter, health care monitoring, and personal care to adults. It provides a protected and safe living environment, and its cost is less than nursing home care. These facilities, which are licensed and monitored by the Department of Health, require that residents be at least 18 years of age. The cost reimbursement paid by Supplemental Security Income is not adequate to meet the special health and psychosocial needs of HIV/AIDS residents. The Department of Health should discuss with appropriate agencies the potential for supplementing the SSI rate paid to residential health care facilities.

Nevertheless, opportunities for HIV/AIDS patient admissions to mainstream residential health care centers should be expanded. The Department of Health should change its licensure regulations to facilitate this integration process. The centers should be modified if necessary to provide for the unique needs and functional abilities of HIV/AIDS patients. Licensure regulations also should be modified to allow residents under 18, so that families can be kept together. The state should mandate ongoing HIV/AIDS education for all residential health care operators and staff as a requirement for licensure or certification.

Long-term Care

Long-term care facilities provide nursing care and supportive services to people with functional impairments due to chronic, and frequently degenerative, functional or cognitive disorders. Some long-term care facilities have developed specialized or subacute care programs to meet the complex needs of certain patients, including those with HIV/AIDS.

> ***"In all of New Jersey, there are only three nursing homes that accept adult patients with HIV infection, only one which accepts people from those counties most affected by AIDS."***
>
> *--Barry Moore*
> *AIDS Committee, National*
> *Association of Social Workers-NJ*
> *Newark Public Meeting*

In fact, nursing homes have a long tradition of caring for patients whose symptomatology--dementia, wasting syndrome leading to physical frailty, and neurological defects--is similar to that of many HIV/AIDS patients. Specialized units for HIV/AIDS patients, staffed with clinical experts in the treatment of HIV/AIDS, would go a long way toward ensuring high-quality care. Nursing homes could also admit AIDS patients on a short-term basis to provide respite for families caring for an AIDS patient living at home.

The state should encourage therefore the development of, and the elimination of obstacles to, access to existing long-term care facilities for HIV/AIDS patients. When possible, AIDS patients should be mainstreamed in these facilities; the basis for admission should be their level of functional capability. Only where necessary should the state encourage the development of new facilities.

Long-term care facilities should provide for those social and developmental needs of HIV/AIDS patients which are distinctly different from those of the geriatric population. Licensure requirements should be modified when necessary to reflect these different needs. The state should develop a process for accelerating the Medicaid review process, which currently prevents HIV/AIDS patients from being admitted until they have acquired a Medicaid number to ensure payment.

The state Medicaid program recently initiated a case-mix reimbursement system for long-term care. This system provides for a minimum level of reimbursement for all facilities tied to nursing hours. Additional reimbursement recognizing seven levels of care based on client need is a component of this system. Implementation of the case-mix reimbursement system should improve access to these facilities for HIV/AIDS patients.

Subacute In-hospital Care

The state should encourage the development of appropriate methods and levels of health care delivery. This need should be met increasingly through community-based service providers.

Accordingly, subacute in-hospital care for HIV/AIDS patients should not be expanded at this time; instead, resources should be diverted to the development of other levels and methods of health care delivery, such as home health and medical day care and nursing homes. A reimbursement rate should be established for patients needing subacute in-hospital care services while awaiting discharge to community-based subacute care providers.

HIV/AIDS-designated Units in Acute Care Units

In the past, there was a question whether or not specific HIV/AIDS-designated units in hospitals should be developed. The questions raised by this issue depend upon where the hospital is located, its size, and the number of HIV/AIDS patients it would treat.

If the hospital is small, a designated unit may not be desirable; in fact, it may actually hinder service delivery and lead to difficulties in maintaining confidentiality. On the other hand, a larger hospital might benefit from such consolidated services as it could treat more HIV/AIDS patients and probably encounter fewer confidentiality problems. Indeed, a designated unit in a large hospital could prove financially and socially advantageous to both HIV/AIDS patients and the hospital.

Accordingly, hospital managements should establish HIV/AIDS-designated units based upon need and the impact on their institutions.

ISSUE: **HIV/AIDS CARE AND TREATMENT FOR SPECIAL POPULATIONS**

BACKGROUND/DISCUSSION:

> ***"Our clients and their families are cut off at the pass, before they can even enter the race."***
>
> *--Bobbie Taylor-Foster*
> *Westside AIDS Project*
> *Camden Public Meeting*

HIV/AIDS presents itself differently in different population groups. Although public awareness campaigns have been able to target those who are at risk, it is more difficult to provide for the unique care and treatment needs of special populations. A concerted effort must be made to ensure that the special needs and individualized treatment programs will be developed as soon as possible.

RECOMMENDATION:

- **It is imperative that HIV/AIDS care and treatment programs meet the often unique needs of special populations.**

IMPLEMENTATION STRATEGY:

- The Department of Health should continue a series of focus groups of special populations and their caregivers to develop appropriate care and treatment programs. Although the care and treatment needs of certain special populations are yet to be fully understood, it is possible to make suggestions for the following groups:

Substance Abusers

> ***"We received money to open up 94 slots last year. People lined up in the morning to get into those slots. Contrary to what people think, people do want treatment."***
>
> *--Carolyn Brigham*
> *Paterson Counseling Center*
> *Newark Public Meeting*

Nearly 60 percent of New Jersey's 10,000 AIDS cases are related to intravenous drug use--the primary mode of HIV transmission in the state. An estimated 50 percent of IVDUs in the state's larger cities are HIV-infected. Most IVDUs are heterosexual and sexually active, and their sexual partners, many of whom are women of childbearing age, are also at risk of infection. Most of the children with AIDS in New Jersey became infected, directly or indirectly, through a drug-using parent. It is becoming clear that alcoholism, crack and cocaine are also having a significant impact on HIV/AIDS transmission as drug exchanges for sexual favors increase the risk of contracting the disease.

In New Jersey, effective drug treatment is synonymous with HIV/AIDS prevention. Similarly, HIV/AIDS care and treatment for substance abusers should be integrated into drug treatment programs; when feasible, substance abuse services should be integrated into other health care facilities and programs. This is not only efficacious, it is cost-effective, because the cost of drug treatment, inpatient or outpatient, is much less than the cost of treating a person with AIDS. For this reason, among many others, drug treatment should be available on demand in New Jersey. This will require a considerable expansion in the number of new outpatient drug-free, methadone maintenance and residential drug treatment slots and rehabilitation facilities for IVDUs and other substance abusers.

Almost two-thirds of all AIDS cases among New Jersey adult and adolescent women are attributable to their own intravenous drug use. ***Woman-specific drug treatment slots are badly needed and should be created.*** There is a particular need for drug treatment services for pregnant women.

Women

> ***"It is incumbent upon New Jersey to join the global community in recognizing women as the fastest growing segment of the population infected with HIV and to become a leader in providing innovative services to women."***
>
> *--Planned Parenthood Association of Mercer County, Inc. Written Testimony*

The HIV/AIDS-related needs of women were attested to by all the women who spoke at the public meetings held in conjunction with the development of this plan. Unlike patterns in most of the rest of the country, in New Jersey a significant number of reported HIV/AIDS cases are women. With the exception of the Women's Clinic at the University of Medicine and Dentistry of New Jersey, services and treatment for women that reflect their special needs have been slow to evolve.

Such gender-specific treatment is particularly critical because recent advances in medical knowledge about HIV/AIDS have discovered manifestations of the disease that are unique to women. Of particular concern are gynecological complications. Some of them--pelvic inflammatory disease and cervical cancer, for example--are potentially life-threatening.

Consequently, the establishment of services and treatment reflecting the specific and distinct needs of women should be one of the highest-priority goals of this HIV/AIDS plan. Considerable attention should particularly be paid to the coordination of service delivery to families. Dependant care services should be made available either in the home or at provider care sites coordinated by the Resource Centers.

The establishment of an ***Office of Women and AIDS*** in the Division of AIDS Prevention and Control to deal with all HIV/AIDS issues specific to women should help focus resources and attention in this area.

Children

Pediatric AIDS is at crisis level in New Jersey. More than nine out of 10 HIV-infected children in the state have at least one parent at risk for AIDS, and five of the 25 cities or communities in the U.S. with the largest number of pediatric AIDS cases are in New Jersey. Because HIV infection presents itself differently in children than in adults, different treatments are required. To be successful, all must include family support and foster care. This support is maximized when programs are community-based and culturally sensitive. A system built around case management and Resource Centers, the system called for in this plan, should deliver these services more efficiently. The pediatric AIDS network should be preserved and expanded where possible to provide family focused care with a multi-disciplinary care team.

Because the course of pediatric HIV infection is so different from that in adults, a great deal of research remains to be done to determine which existing HIV/AIDS-related drugs are effective for children, and to develop new ones. Not enough children have been participating in experimental drug trials; in the future, their inclusion in experimental protocols, when medically appropriate, should be encouraged.

Minorities

> ***"[This plan] will fail unless we seek to deal with bigotry and racism in this industry."***
>
> *--Dr. Francis Blackman*
> *North Jersey Medical Society*
> *Newark Public Meeting*

About two-thirds of all New Jersey AIDS cases are members of minority groups. This is particularly significant and problematical in that these groups have historically had less access to ***all*** health services than have whites. The HIV/AIDS epidemic only makes improved access to medical care and treatment even more urgent. Community-based organizations are among the best and most cost-effective providers of services to minorities. ***One of the chief tasks of the case management and Resource Center system recommended in plan will be to coordinate HIV/AIDS care and treatment services in high-risk minority communities.***

The need for HIV/AIDS services is particularly acute among minority women, many of whom were burdened with myriad social and medical problems before the age of AIDS. Care and treatment services should be oriented to the specific needs of minority women, such as child care, support services for caregivers, etc. They should be encouraged to participate in ongoing and future clinical trials of HIV/AIDS-related drugs, unless such participation is medically contraindicated.

Incarcerated Persons

As was discussed in the Education and Prevention section of this report, the incidence of HIV infection and AIDS in New Jersey's incarcerated population is very high, and its linkage to substance abuse particularly striking. This report therefore recommends as a matter of some urgency the development of a mechanism creating a uniform standard of HIV education, testing and counseling, and care and treatment for inmates in the entire correctional system.

> ***"I have a son who has tested HIV-positive. He was incarcerated for about a year prior to finding out that he was HIV-positive. In the institution he got no type of services had it not been for my intervention, and that's because being his mother, working for an AIDS program. I knew what his rights were."***
>
> *--Joyce Henten*
> *New Jersey Assoc. of Corrections*
> *New Brunswick Public Meeting*

The chief assumption underlying such a policy is not only that standardized and coordinated care and treatment services should be available to all incarcerated persons, but that these persons are entitled to the same HIV/AIDS medical treatments as the rest of the state's residents.

A first step in this direction would be the examination and modification of all current rules and regulations prohibiting incarcerated persons from voluntarily participating in clinical trials and experimental protocols of HIV/AIDS-related experimental medications and therapies. The Office of the Attorney General has already authorized physicians to use "innovative or experimental treatment" for inmates if it is deemed to be beneficial and the patient's consent has been obtained.

The state should also establish a broad treatment and prophylaxis program to accompany the voluntary HIV testing and counseling of all inmates. The Department of Corrections estimates the cost of such a program for 60 percent of current inmates and all new admissions at $12 million for FY92.

The Department of Corrections has requested the assistance of the Department of Health in locating long-term care facilities willing to admit incarcerated persons with HIV/AIDS. The state should also consider the establishment of an intermediate-level nursing care facility designated for the correctional population. The up-front costs incurred in such a project would eventually be offset by the cost-effectiveness of shifting inmates from an acute-care setting to more appropriate HIV/AIDS long-term care.

ISSUE: **HEALTH CARE PERSONNEL**

BACKGROUND/DISCUSSION:

The serious shortage of trained health care professionals, both nationally and in New Jersey, has been exacerbated by the HIV/AIDS epidemic. The care and treatment system for HIV/AIDS patients is overwhelmed at every level of care. An urgent need for medical and other health care personnel to treat the inexorably increasing numbers of people affected by this epidemic exists.

> ***"Currently, patients wait many hours when they go to the clinic to see a doctor, and they mainly see the doctor for a few minutes when, indeed, a physician's assistant might just as easily be able to perform the services and provide the patient with more advice--and more time."***
>
> *--William Orr*
> *North Jersey Community*
> *Research Initiative*
> *New Brunswick Public Meeting*

The participation of a corps of physicians' assistants should greatly improve HIV/AIDS service provision in all health care settings. Neglected geographic locations and populations would also benefit from the services of physicians' assistants. New Jersey is one of the few states in which physicians' assistants are not valued members of the staffs of hospitals, clinics, mental health centers, and substance abuse and prison health centers. Nurse practitioners are another important provider group which should be deployed, particularly in high epidemic areas.

RECOMMENDATION:

- **The Department of Health should examine ways to alleviate the shortage of health care personnel generally, and the shortage of personnel willing and able to treat HIV/AIDS patients in particular.**

IMPLEMENTATION STRATEGIES:

- The Department of Health should work with the State Legislature to immediately enact legislation allowing for the licensing and practice of physicians' assistants in the state.

- The state should also consider a program to either provide tuition or buy-out loans of health care personnel willing to work in the field of HIV/AIDS.

ISSUE: **GENERAL HOUSING**

BACKGROUND/DISCUSSION:

As the number of persons with HIV/AIDS--many of whom are socially disenfranchised and/or homeless--increases, a serious attempt to provide adequate housing at minimal financial and social cost needs to be undertaken. The goal of the state should be to meet the needs of persons with HIV/AIDS by using mainstream housing whenever possible to maintain the cohesiveness of the family and community. When this is not possible, other housing options must be explored.

> ***"[We need to] alleviate the need for homeless AIDS patients to find makeshift accommodations in junked automobiles, abandoned buildings, subway stations or otherwise totally inappropriate dwellings that are not public health facilities, including rooming houses and existing homeless shelters."***
>
> *--Derek Winans*
> *Newark Community Foundation for PWA's*
> *Newark Public Meeting*

RECOMMENDATION:

- **The state should first perform a housing needs assessment for people with HIV disease and AIDS, and innovative types of housing should be funded and developed to meet the diverse needs of this population. Along with mainstream housing, these include private sector apartments, boarding homes, and group homes designated for HIV/AIDS patients.**

IMPLEMENTATION STRATEGY:

In order to facilitate this process, the state should revise regulatory barriers between state departments which hinder access to housing and the provision of needed health services. It should also vigorously enforce the existing federal and state laws and regulations which bar discrimination in housing. All civil rights violations should be investigated.

The dialogue initiated in the process of developing this plan between the Department of Community Affairs' Bureau of Housing Services and the Departments of Health and Human Services on comprehensive planning for the homeless should continue. The Department of Health should continue to explore the availability of resources, such as federal McKinney funding, for housing initiatives.

Additional Implementation Strategy:

An ongoing Interdepartmental Housing Initiatives Task Force, with representatives from Departments of Community Affairs, Human Services, and Health, should be convened to explore housing programs and funding sources to address the diverse housing needs of the HIV/AIDS population, including the use of Homelessness Prevention, Transitional Housing, Life Safety Improvement and Emergency Housing Program funds.

The state should also take steps to coordinate information and services on housing, licensing, regulations and certificates of need at the state level by centralizing this in a single location.

The Department of Health, in coordination with other state agencies, should:

- pursue federal grants for the support of housing for persons with HIV/AIDS infection;

- promote increased access to existing housing and rental assistance programs for persons with HIV infection;

- continue to educate local officials, community leaders and neighborhood groups in order to ameliorate negative attitudes and discrimination that often hinder the development of housing alternatives for persons with AIDS; and,

- develop and distribute a state resource booklet that identifies state and federal resources for support of permanent housing programs for persons with HIV/AIDS, including rental assistance and the development and operation of group residences.

Finally, the state should initiate these recommendations and suggested mechanisms for housing for the HIV/AIDS population as a pilot project that can then be utilized for other groups with similar housing needs.

INTERAGENCY COORDINATION AND EVALUATION OF HIV/AIDS ACTIVITIES

The face of the HIV/AIDS epidemic in New Jersey is constantly changing. Its scope is broad, the problems and issues it poses are complex and cross-cutting, and the programs needed to deal with it are numerous and diverse. An epidemic like HIV/AIDS demands not only a comprehensive response, but also one that is carefully coordinated, if it is to ensure that all necessary services are provided efficiently and without duplication.

Considerable resources are now earmarked for HIV/AIDS services and prevention programs. In the face of so serious a public health crisis, too many programs have in the past been inadequately monitored to determine whether or not they accomplished the ends for which they were designed. It is essential that there be an evaluation component or mechanism built into these services and programs.

ISSUE: **INTERAGENCY AIDS ACTIVITIES**

> ***"You have programs scattered throughout all the various divisions in the state. They need to be under one umbrella; they need to talk to each other. They don't know what the right hand and the left hand is doing. There's a lot of overlap and un-coordination in these services."***
>
> *--Katie Leone*
> *Coalition of AIDS-Passaic County*
> *Camden Public Meeting*

BACKGROUND/DISCUSSION:

The Departments of the State of New Jersey HIV/AIDS Advisory Committee consisted of the commissioners or designees of several key state departments. This group was able to identify, for the first time, significant opportunities for cooperation between their agencies to provide better services to the people of the state. The committee discussed programs which, with minimal effort, could serve dual purposes--to provide their home agency with their designated program, while also promoting an AIDS message or service.

RECOMMENDATION:

- **Departments of the State of New Jersey should make every effort to identify opportunities for collaboration in confronting the HIV/AIDS epidemic.**

IMPLEMENTATION STRATEGIES:

- **The Department of Health will work with the Department of Corrections** to initiate blinded seroprevalence testing for persons entering state correctional facilities.
- **The Department of Health, working with the Department of Labor,** will work more closely with New Jersey businesses and local governments to educate and inform their employees--via pay check, telephone bill and/or utility bill inserts--about HIV/AIDS related issues.

- **The Department of Health should establish a relationship with the Department of Human Service's public assistance programs such as the state's welfare program,** to disseminate educational materials to special populations that may be a risk of HIV infection.

- **The Departments of Health will work with the Department of Education** to train substance awareness coordinators already in place at the secondary school level in HIV/AIDS prevention education; training can also be extended to guidance counselors, school nurses and school social workers.

- **The Departments of Education and Health will continue to work together** on regulations for school attendance of HIV-infected children.

- **The Departments of Health and Higher Education should collaborate** on an HIV/AIDS curriculum for college and university students.

- **The Departments of Health and Human Services should work together** to ensure that the New Jersey Schoolbased Youth Services Program, which offers an array of health, employment, recreation, and family assistance services, also include an HIV/AIDS education and counseling component.

- For school-age children and adolescents not in school, **the state should coordinate efforts between the Departments of Community Affairs, Labor, Health, and Human Services** to provide training and technical assistance to community-based organizations and youth corps agencies that provide services to out-of-school youth.

- The state should provide a small amount of additional funding to support HIV education prevention efforts within programs like College Bound, the Retention Initiative Grant Program, and the Education Opportunity Fund Program.

- **The Department of Health will work with the Department of Human Services** to develop appropriate programs for institutionalized populations.

- The state should coordinate and improve its prevention and education services to all New Jersey workers. It should create an AIDS Awareness Council of diverse membership to coordinate and plan policies and awareness programs on behalf of all New Jersey workers.

- **The Department of Health will work with UMDNJ** to develop training externships for practicing physicians who wish to become familiar with state-of-the-art HIV management.

- **The Department of Health will discuss with the Department of Human Services** the potential for a state supplement to the Supplemental Security Income (SSI) rate paid to Residential Health Care Facilities.

- **The Department of Human Services with the assistance of the Department of Health** should develop a process for accelerating the Medicaid review process, which currently prevents HIV/AIDS patients from being admitted to nursing homes until they have acquired a Medicaid number to ensure payment.

- **The state should convene an ongoing Interdepartmental Housing Initiatives Task Force (comprised of representatives from Departments of Community Affairs, Human Services, and Health)** to explore housing programs and funding sources and opportunities that will address the diverse housing needs of the HIV/AIDS population, including the use of Homelessness Prevention, Transitional Housing, Life Safety Improvement Program and Emergency Housing Program funds.

- The state should select a single agency to oversee licensing issues for all housing and related services with input from the Departments of Health, Human Services, and Community Affairs.

- **The Divisions of AIDS Prevention and Control and Occupational and Environmental Health in cooperation with the Department of Personnel** should develop formal policy action to be taken when state workers are exposed to HIV virus during the course of their normal duties.

- **The Departments of Health, Human Services, and Corrections** should pursue the possibility of reducing costs by buying life-prolonging medications in bulk.

ISSUE: **EVALUATION OF EXISTING AND FUTURE HIV/AIDS SERVICES AND PROGRAMS**

BACKGROUND/DISCUSSION:

> *"The structure of who is doing what needs to be reviewed."*
>
> *--Rosemarie, PWA*
> *Newark Public Meeting*

The face of the HIV/AIDS epidemic in New Jersey is continually evolving. Its scope is broad, the problems and issues it poses are complex and cross-cutting. The programs needed to deal with this disease are numerous and diverse. As knowledge about HIV/AIDS increases, policy responses must reflect these changes. The evaluation component of this plan is meant to tell us where we have been, where we are, and were we ought to go.

Evaluation can be divided into two categories: evaluation of program performance and evaluation of objectives or outcomes. Evaluation of program performance determines whether or not administrative goals were met. Outcome evaluation takes the longer view by determining whether or not more long-term objectives have been met, and significant progress made. Both types of evaluation are needed.

RECOMMENDATION:

- **HIV/AIDS services and programs should be evaluated regularly to ensure that limited resources are directed to priority programs which are able to demonstrate their effectiveness.**

IMPLEMENTATION STRATEGIES:

- The Division of AIDS will begin to enhance its capacity for program evaluation of all activities funded in the future. The division has already begun to do this in its recent Request for Application for Prevention for federally supported prevention and education efforts.

- Proposed applicants should be asked to design proposals to reach populations within target geographic areas. Successful grantees should be required to determine measurable, quantifiable goals for all program activities. Division of AIDS staff will analyze program performance during the grant period.

- The Division of AIDS will actively dedicate a small percentage of grant funds for program evaluation efforts. The division will undertake a review of these efforts to determine whether they have achieved the objectives they were funded to achieve. This assessment will be undertaken by division staff.

- For future service initiatives, the Department of Health staff will identify the policy which service programs will be designed to address. Priority will be given to issues essential to the improvement of the health or quality of life of HIV-infected persons.

- The Department of Health will attempt to supplement in-house staff with outside assistance. The AIDS Division will work with in-state agencies including universities and/or colleges with expertise in assessment and evaluation of service programs.

- Programs that fail to meet planned performance goals should not be refunded from year to year. The division must be more proactive in identifying and responding to needed changes in program focus as the epidemic evolves.

ISSUE: CONTINUATION OF THE PLANNING PROCESS

BACKGROUND/DISCUSSION:

All the groups involved in the development of this plan have stressed the need for continuation of the process. Indeed, we have felt that this report is not the end of the process but rather the beginning of a series of initiatives that will reflect the progress made in treating HIV-infected persons in the state as well as the changing character of the epidemic.

> ***"In order for New Jersey to become a role model in establishing an effective, responsible statewide agenda in dealing with the AIDS crisis, we must formulate a far-reaching plan, including the Community Advisory Committee, consisting of people living with AIDS, their families and caretakers, medical experts, activitists, people of color."***
>
> *--Sebastian Porridge*
> *ACTUP South Jersey*
> *Camden Public Meeting*

RECOMMENDATION:

- **The state should formalize a permanent AIDS Advisory Council that is appointed by the Governor upon recommendation of the Commissioner of Health.**

IMPLEMENTATION STRATEGIES:

- The Commissioner of Health will request that the Governor appoint an AIDS Advisory Council to advise the department on all issues relating to the AIDS epidemic in New Jersey. The council will be composed of health care providers, business leaders, labor representatives, educators, and other private citizens. The council will also have as members of persons with AIDS, and reflect the cultural and racial demographics of persons with AIDS in New Jersey.

- The first task of this group will be to monitor the Department of Health's progress in implementing the recommendations of the plan. The council should also be required to submit an annual report to the Governor on its findings.

- The department will continue its efforts to obtain additional funds from CDC for special projects as such funds become available. However, it should be noted that even federally-funded projects require some expenditure of state resources. The benefits to be derived from such projects in additional surveillance capacity are well worth the expenditure of additional state funds.

FINANCING THE PLAN

FINANCING HIV/AIDS SERVICES

The economic cost of HIV/AIDS early intervention, extended care and treatment is considerable. However, the human cost of living and dying with dignity must be taken into account as well. Financing strategies must attempt to balance the two costs to provide the best possible care for the greatest number of people. Given the state's current fiscal situation, this will be no easy task. These financing strategies, then, will necessitate our taking several different approaches in supporting the activities that are recommended.

- The Division of AIDS Prevention and Control will undertake an assessment of all activities currently supported by state funds to ensure that state dollars are being expended in a manner consistent with the priorities set forth in this document. FY91 state grant funds total $10,491,000.

- The division will use limited federal funds as efficiently as possible in order to maximize their effectiveness. In addition, the division will seek additional federal and private funds. The division should add a grant-writing team to its staff to enhance this search for funding. This team should also be made available to assist community-based organizations in their quest for additional HIV/AIDS funding. The cost of a grant-writing team is estimated to be $110,000/year.

- The Department of Health will improve cooperation and coordination with other state agencies to avoid duplication and increase efficiency, and must work closely with the Governor, the State Legislature and private sector funders to obtain new monies.

- The Division of AIDS will continue to use federal CDC funds to support seroprevalence, surveillance, counseling and testing, partner notification, education and prevention activities. Funds for FY91 total $7,553,000.

- The division will allocate state-appropriated FY92 funds to meet the priorities in this plan, including the establishment of three to five Resource Centers around the state. The division will, in subsequent years, phase in additional Resource Centers. It is estimated that the cost of each center will be approximately $175,000/year.

- The division will apply for new federal funds in the amount of $4,215,417 under Title II of the 1990 Ryan White CARE Act to continue the AIDS drug distribution program and a home and community-based services demonstration effort. The division will

also use these funds to establish HIV services consortia across the state. Fifty percent, or $2,107,709, of the funds must be used for consortia; a state match requirement of $843,083 will be appropriated from existing funds.

MEDICAID SUPPORT FOR HIV/AIDS SERVICES

The state Medicaid program plays a major role in the financing of medical care for HIV/AIDS patients. A recent review of inpatient admissions to selected hospitals indicates that Medicaid pays for 41 percent of all HIV/AIDS-related services. It is, therefore, vital that the Department of Health work closely with the Medicaid program to ensure adequate and appropriate reimbursement for existing and proposed services.

The department also will work closely with the Medicaid program to improve financing of current services that are critical to HIV-infected individuals. The department also will request that the Medicaid program consider coverage of the following:

- targeted case management for HIV-infected persons;
- continuation of employment-based health insurance coverage for HIV-infected persons eligible to continue health insurance under COBRA regulations;
- appropriate incentives via the new case-mix reimbursement system for nursing homes to admit HIV-infected persons.

The department will discuss with the Department of Human Services and other state agencies the need to supplement the SSI rate for residential health care facilities which serve HIV-infected patients.

NEW FUNDS FOR HIV/AIDS SERVICES

Many of the services or activities identified in the plan will require new funds. The Department of Health must work closely with the Governor and Legislature to stress the importance of new funding in specific areas and to identify new sources of funding. Service expansion can be phased in over a three-year period. This approach lessons the impact on any one fiscal year while allowing time for the provider community to develop the increased capacity.

The department will discuss with the Treasurer and the Governor the feasibility of using of Casino Tax Revenues to support HIV/AIDS services. This tax revenue is constitutionally dedicated to support programs for the disabled and the elderly. The 1990 Americans with Disabilities Act (PL 101-

336) includes persons with HIV/AIDS as members of the class of disabled who receive specific protection from discrimination. They, too, should be considered disabled under the Casino Tax Revenues program.

CONCLUSION

CONCLUSION

THE DEVELOPMENT of this statewide HIV/AIDS plan began 100 days ago, at the behest of Governor Florio. Its submission marks not the end but the beginning of a dynamic and ongoing planning process for HIV/AIDS issues which will be continued by the creation of an AIDS Advisory Council.

At each of four public meetings held in November and December, the people in the front lines of the war on AIDS--and people with HIV/AIDS-- implored those participating in the development of this plan to ***make some sense*** of our response to the HIV/AIDS epidemic.

We heard them. The common thread running through this report is the need to develop a coordinated plan to fight AIDS; to draw up a blueprint for action that optimizes and maximizes the resources we are expending to learn more about the epidemic, to arrest its spread, and to care for its stricken.

Times are tough; resources are scare. But the recommendations set forth in this report deserve careful consideration by policymakers--not only because they are the product of much time and concerted effort, but because they are the best answer we can devise to a heartfelt, eloquent cry for help.

APPENDIX I

THE HIV/AIDS COMMUNITY ADVISORY COMMITTEE'S RECOMMENDATIONS TO THE COMMISSIONER OF HEALTH JANUARY 1991

INTRODUCTION

The HIV/AIDS Community Advisory Committee was composed of more than 40 members, representing the broadest range of expertise in, and involvement with, the HIV/AIDS epidemic in New Jersey. The Committee was divided into three subgroups dealing with the following sets of issues relevant to the epidemic: epidemiology and prevention, services and treatment, and regulation and legislation. The contribution of the Community Advisory Committee has been invaluable.

The documents which follow contain a discussion of the major issues addressed by each of the three subgroups of the Community Advisory Committee, as well as by the other two committees involved in the planning effort, the Departments of the State of New Jersey Advisory Committee, and the Department of Health Advisory Committee. One or more related recommendations--and an implementation strategy--accompany the discussion of each issue.

PREVENTION AND EDUCATION

ISSUE: ***PREVENTION OF HIV TRANSMISSION THROUGH THE SALE OR EXCHANGE OF NEEDLES AND SYRINGES***

BACKGROUND/DISCUSSION:

Since transmission of the HIV/AIDS virus through IVDU is particularly prevalent in New Jersey, (approximately two-thirds of all cases are IVDU-related) it is critical that education and drug treatment prevention measures be increased to meet the demand.

However, even if drug treatment was available upon demand, many users would continue to inject drugs. The availability of sterile needles and syringes must be considered an important component in any effort to prevent the transmission of HIV/AIDS. The distribution of needles and syringes to the drug-using population is a health issue, not a political one; it is meant to prevent the spread of disease. Needles and syringes are currently available for over-the-counter purchase in 39 states. New Jersey is one of only 11 states which prohibit such purchases.

RECOMMENDATIONS:

- *Sterile hypodermic equipment should be made available for over-the-counter sale in New Jersey.*
- *Needle-exchange demonstration projects should be developed and financed in selected, accessible locations.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should assist in the immediate development and adoption of over-the-counter needle legislation.*
- *The Department of Health should pursue the development of a needle-exchange demonstration project. This project should include a educational and a surveillance component.*

ISSUE: ***THE PURCHASE AND DISTRIBUTION OF CONDOMS TO REDUCE THE RISK OF HIV TRANSMISSION***

BACKGROUND/DISCUSSION:

Although the modes of transmission for HIV infection vary, the vast majority of cases and the greatest potential risk of infection are at least related to sexual activity. For those who are sexually active, the use of condoms and other barrier devices has been demonstrated to be effective in helping to prevent the spread of sexually transmitted diseases. The federal government recommends the use of condoms to help reduce the transmission of HIV.

Current Department of Health policy limits the purchase of condoms to federal funds and their distribution to counseling and testing programs. It therefore limits the number of condoms which can be purchased and distributed, and precludes community-based organizations which receive funding for prevention and education from purchasing condoms with these funds.

RECOMMENDATION:

- *The Department of Health should change its policy to allow state funds to be used for the purchase and distribution of condoms in certain health care facilities and drug treatment programs.*

ISSUE: ***AIDS SURVEILLANCE***

BACKGROUND/DISCUSSION:

The goal of AIDS surveillance is to improve the identification and reporting of AIDS cases and related conditions and to conduct epidemiological investigations of selected cases. The current Centers for Disease Control (CDC) case definition of AIDS is incomplete, and needs to be expanded to include significant HIV-related illness in women, adolescents, children, substance abusers and the elderly.

Research and data collection are needed to support this reevaluation of the CDC's case definition, especially in regard to the special populations named above. Many of these groups have until now been denied recognition of their illness and/or eligibility for entitlement programs; a revision of the AIDS case definition should diminish this discrimination.

The state needs to explore any and all avenues to expand the AIDS case definition and the current statutory disbursement entitlement issues.

RECOMMENDATIONS:

- *All avenues to expand the CDC AIDS case definition and the related reimbursement and entitlement issues must be explored immediately.*
- *Female-specific HIV morbidity and mortality must be established as an important consideration for New Jersey Public Health Research and Policy.*
- *The state should begin to collect data on the many female-specific diseases, infections and/or cancers which define the AIDS syndrome in women, in order to support its effort to effect a change in the CDC definition. *For a list of some of these conditions, please refer to the appendix.*

IMPLEMENTATION STRATEGY:

- *The state should immediately pursue action, legal and otherwise, to challenge the CDC AIDS case definition. For example, it should join the suit against the Social Security Administration, which is currently using the CDC definition inappropriately to determine eligibility for benefits.*
- *Federal and state funds should be sought to investigate hospital and clinic records to more accurately describe the course of HIV infection in women.*
- *The AIDS mortality study should be extended to answer questions on female mortality.*
- *The Commissioner of Health should write a letter to the CDC urging them to look at the data supporting a broader AIDS case definition.*

ISSUE: ***SURVEILLANCE FOR HIV INFECTION***

BACKGROUND/DISCUSSION:

HIV infection and AIDS are currently underreported. In order to partially remedy this problem, blinded HIV seroprevalence studies are needed for certain populations not yet surveyed. These include inmates in state prisons and county jails, individuals in inpatient and outpatient settings, and high school and college students. These studies should be part of an overall effort to make HIV/AIDS statistics more accessible and comprehensible to the general public.

RECOMMENDATIONS:

- *Blinded seroprevalence studies should be expanded to include populations not yet surveyed in order that surveillance data accurately reflect true seroprevalence in these populations.*
- *HIV/AIDS statistics should be made more accessible and understandable to the general public.*
- *The State should help to improve the understanding of HIV/AIDS reporting statistics, so the public realizes that CDC AIDS data is underreported by anywhere from 10 to 40 percent.*
- *State materials on HIV/AIDS should be marked with an asterisk (*) to indicate underreporting whenever a CDC statistic is used.*

IMPLEMENTATION STRATEGY:

- *Seroprevalence studies should be conducted on blinded samples upon entrance to state prisons and county jails.*
- *Blinded seroprevalence testing should be conducted in certain settings and populations, including clinic and hospital patients, schools and colleges.*

ISSUE: ***HIV PREVENTION AND EDUCATION PROGRAMS (GENERAL PUBLIC)***

BACKGROUND/DISCUSSION:

AIDS is a serious health problem, and the extent and complexity of the epidemic and its impact on individuals, institutions and the public psyche are increasing dramatically. Even where general education efforts have worked fairly well, indications from health workers in AIDS suggest that sexually active persons are aware of the AIDS epidemic and reasonably informed about HIV transmission, but have not done enough to modify risky behavior.

Badly needed is an innovative, well-coordinated, and comprehensive statewide multi-media campaign to increase the general public's knowledge of AIDS, risky behaviors, and modes of transmission.

More specifically, education through the use of literature is thought to be a excellent method of AIDS and HIV prevention. Nevertheless, this information has not been made readily available to patients and clients in professional and health care offices and waiting rooms. There has been a lack of sufficient culturally sensitive and linguistically appropriate prevention and education materials in these offices and waiting rooms.

Many physicians and professionals believe that the availability of these materials in their offices will broadcast a message to their clientele that they are treating AIDS and HIV-infected patients and that they will consequently lose patients. This attitude, both on the part of professionals and the general public alike, is too often based on ignorance of the disease and fear of those infected.

RECOMMENDATIONS:

- *The State should develop and implement coordinated statewide HIV/AIDS education programs and campaigns which are culturally sensitive, non- heterosexist and gender-specific in private and public facilities, educational institutions and public transportation.*

- *Legislation should be enacted to ensure that Department of Health-approved AIDS and HIV educational materials addressing prevention, transmission, and treatment are made available in full view to clients and patients, in all health care offices and/or waiting rooms, including private physician offices.*

IMPLEMENTATION STRATEGY:

- *HIV/AIDS information should be more widely distributed.*

- *Information should be widely disseminated to both the broadcast and print media.*

- *The dynamics of financing and distributing this literature and other information need to be addressed.*

- *All public and private health care providers should be required to have HIV/AIDS information in plan view in their public waiting areas.*

- *The Department of Health should plan and coordinate the education of health care professionals so that they themselves understand the importance of AIDS/HIV intervention, and understand that their offices are instrumental sources of information for their clientele.*

- *The Department of Health shall encourage and assist in the development and adoption of any necessary and appropriate legislation or regulation.*

- *In order for prevention and education to be taken seriously, the Governor must: 1) be properly educated 2) take the lead, and 3) speak out more frequently to the public.*

ISSUE: HIV PREVENTION AND EDUCATION PROGRAMS (SCHOOLS & COLLEGES)

BACKGROUND/DISCUSSION:

HIV/AIDS is spreading among teenagers and young adults at an alarming rate. A recent study estimated that as many as one in five hundred college students may be infected with the virus. The goal of youth educational efforts is to increase the awareness and understanding of school- and college-aged students on AIDS and risk behaviors to decrease the spread of AIDS/HIV infection in this population. It should also alter negative attitudes about those who are infected or at risk, and promote a climate in which such individuals can be cared for. The creation of this climate depends on the elimination of the irrational fears which the epidemic has engendered. Thus AIDS education includes efforts to predispose people to be more open-minded about permitting needed education, counseling and testing, and residential programs to locate in their communities, and to reduce the anxieties about the disease which have placed roadblocks in the way of this process in the past.

Although AIDS education is mandated in New Jersey schools, a specific curriculum is not. There is little evidence that students are receiving an accurate or comprehensive education on the subject. School-based HIV/AIDS educational initiatives must present a consistent, full view of the disease and its means of prevention.

Since college may be considered a time for experimentation, physically as well as intellectually, a comprehensive plan to inform and educate students attending the 48 state and community colleges should be considered.

The Departments of Education and Health have been working on revisions to the regulations for attendance at school of HIV-infected children. Also needed are new methods of disseminating information on AIDS prevention and risk reduction to youth in areas with high AIDS prevalence who may not be in school.

RECOMMENDATIONS:

- *Educational and surveillance initiatives should be intensified in primary schools, high schools and colleges and universities.*
- *The Legislature should mandate statewide implementation of an AIDS education curriculum for grades K-12 as developed by the State Department of Education in consultation with the Commissioner of Health.*
- *An HIV/AIDS education curriculum for college and university students should also be developed by the Department of Health and the Department of Higher Education*

IMPLEMENTATION STRATEGY:

- *The state should investigate methods of implementing and ensuring the content of HIV/AIDS awareness taught at the local school level, in accordance with the guidelines promulgated by the Department of Education.*
- *All Departments should work together to educate school- and college-age youth. The Department of Health should take the lead in providing training and education to professionals in schools.*
- *Annual school-based knowledge, attitude and behavior studies should be initiated.*
- *Educational program priority should be given to peer group prevention activities.*
- *The state should develop an AIDS instructional guide for junior and senior high school students to assist them in peer education efforts.*
- *The Department of Education should work with local school districts to evaluate their AIDS instruction and to train staff in implementing their instruction guide.*
- *The state should support the cross-training of the over 200 substance abuse counselors already in place at the high school level to include HIV/AIDS education. Within the next 12-15 months, train the counselors; then train guidance counselors and nurses, then teachers.*
- *State support of college services and programs which train people to provide AIDS information should be expanded.*
- *The state should coordinate efforts between the Departments of Community Affairs and Health to provide training and technical assistance to community-based organizations and youth corps agencies that provide services to out-of-school youth; with the Department of Human Services, to identify teams to be trained to effectively educate children with special needs about health education and HIV awareness; with the Department of Corrections, to accelerate training on HIV prevention to minority and high-risk youth who either reside at correctional centers or attend programming.*

ISSUE: ***PREVENTION AND EDUCATION (HEALTH PROFESSIONALS)***

BACKGROUND/DISCUSSION:

It is vitally important to enhance the expertise of the health care community and direct service professionals on AIDS-related education and prevention issues, in order to better prepare them to counsel their patients/clients on this disease and its modes of transmission. Health care workers and service professionals, when adequately prepared with accurate information regarding AIDS and HIV, can also more easily deal with infected and symptomatic individuals in a sensitive, objective manner. This will facilitate appropriate care and treatment.

An effort to develop and disseminate AIDS information to the state health care community and to direct service professionals has already begun. However, more needs to be done. To cite several examples, some health care workers need special guidelines to enhance their ability to provide quality home-care services. In-service training programs and educational material to health care providers who work in state mental health institutions might also be a part of this effort. Infection-control practitioners should be trained statewide so that they can act as in-house trainers in each of their respective hospitals or institutions.

As the prevalence of HIV among hospital populations continues to grow, it will be necessary to resolve the conflict between patient rights and health worker rights in regard to HIV testing and risk of exposure.

RECOMMENDATION:

- *The State should mandate that all health professionals and those providing direct services to persons with AIDS or HIV disease (e.g. law enforcement personnel, fire fighters, correctional officers) receive continuing HIV/AIDS education as a requirement for licensure or certification. (There is a minority opinion on this issue--that while it is desirable to provide this education, it is unwise to link it to licensure or certification.)*

IMPLEMENTATION STRATEGY:

- *The Department of Health should be responsible for coordinating the development of the educational program outline that is to be used for training. The program shall include information regarding infection, prevention, treatment, and sensitivity training.*
- *The State should promote timely and effective enforcement of penalties for discriminatory acts by health care providers and develop an accessible, "patient friendly" reporting method.*
- *The Department of Health should encourage and assist in the development and adoption of any necessary and appropriate legislation or regulation.*

ISSUE: ***HIV PREVENTION EDUCATION FOR GAY AND BISEXUAL MEN AND FOR LESBIAN AND BISEXUAL WOMEN***

BACKGROUND/DISCUSSION:

At the present time, there are too few AIDS programs in the southern region of the state which provide adequate AIDS prevention education specifically targeted to gay and bisexual men and lesbian and bisexual women. This may be attributable, at least in part, to New Jersey's distinction as the only state in which reported AIDS cases in IVDUs exceed those among gay and bisexual men, as well as to ignorance and fear of these men and of lesbian and bisexual women.

It has been assumed that the incidence of AIDS in the gay population of the state is a diminishing problem. This is not the case. In ten counties in the state, the primary mode of transmission of HIV continues to be unprotected sex between two men. Although there were some successful prevention programs targeted to gay men and lesbians in the past, these programs exist now only as remnants, or are considerably less active. A certain segment of the population may have received the prevention message. But there is a growing number of younger people, including lesbian and gay adolescents, who remain uninformed. It is therefore imperative that efforts be directed toward gay and bisexual men and lesbians and bisexual women to ensure that the incidence of HIV infection and AIDS does not increase.

RECOMMENDATION:

- *The Department of Health should issue a sufficient number of Requests for Proposals for prevention/education projects targeted to the above-named populations in its next round of funding for community-based organizations.*

IMPLEMENTATION STRATEGY:

- *Gay and bisexual men and lesbian and bisexual women should be included in the target populations for all funded projects when appropriate.*

- *The Division of AIDS should review HIV-prevention materials currently distributed as well as training programs sponsored by the division in order to identify and/or develop materials and strategies which are effective in providing prevention education to gay/bisexual men and lesbian/bisexual women, and to identify and/or develop materials and strategies to assist providers in imparting effective and sensitive messages to these populations.*

ISSUE: ***GOVERNOR'S INITIATIVES AND COORDINATION***

BACKGROUND/DISCUSSION:

The Governor's leadership is needed to bring HIV/AIDS prevention messages, treatment possibilities and human dignity issues before the public and the Legislature. The HIV/AIDS Advisory Committee was a start, but important issues which could not be addressed in such a short time remain.

RECOMMENDATION:

- *The Governor should take the lead in promoting HIV/AIDS prevention and education activities in the state.*

CARE AND TREATMENT

IMPLEMENTATION STRATEGY:

- *The Governor should extend the planning process beyond 90 days by designating an ongoing body like the Community Advisory Committee to recommend changes and monitor progress.*

- *The Governor should establish a "Health Awareness Action Award" for private industries for prevention education activities.*

- *The Governor should speak publicly about HIV/AIDS prevention, treatment and services in New Jersey; for example, in the "State of the State" Address.*

ISSUE: ***MEDICAL DAY CARE***

BACKGROUND/DISCUSSION:

Medical day care centers deliver preventive, diagnostic, therapeutic, and rehabilitative services under medical supervision to meet the needs of functionally impaired adult patients. They provide service for up to 12 hours a day, and are licensed and monitored by the Department of Health.

Respite care for those who are caregiving family members and for significant others is also a major support function of medical day care centers. This support allows individual caregivers the flexibility to maintain employment and a normal lifestyle while lessening the guilt associated with "abandoning" their loved one.

The cost of medical day care is less than that of long-term care and offers many of the same services while providing a home-like, supportive setting. The home-like setting can be excellent for symptomatic HIV and AIDS patients lacking adequate housing, and day care centers' socialization activities are also useful.

However, existing medical day care centers are generally designed and structured to meet the needs of a frail elderly population; AIDS patients who are typically young adults and who may have drug abuse problems will require some services that are not available in most existing medical day care programs, such as different recreational activities and drug treatment.

Moreover, operators of medical day care programs for AIDS patients indicate that reimbursement may not be adequate for meeting the special needs, such as nutritional support, social activities, family support, and education, of HIV/AIDS clients. Medicaid reimbursement for medical day care is approximately $38 per person per diem, however, while AIDS Community Care Alternatives Program (ACCAP) reimbursement is approximately $58 per person per day.

Finally, licensure requirements state that patients must be 16 years of age or older; therefore, families with young children cannot be treated as a family unit. However, this licensure requirement could probably be waived for a special program.

RECOMMENDATION:

- *Medical day care should be expanded statewide to provide services appropriate to the special needs of HIV/AIDS patients.*

IMPLEMENTATION STRATEGY:

- *Medical care insurance reimbursement should be related to the services provided, such as counseling and occupational therapy.*
- *Licensure requirements setting age limits should be eliminated, in order that young children and their parents may be treated as a family unit*
- *The State should expand hours of operation for medical day care beyond the current regulation of hours 7am to 7pm, in order to meet the needs of clients.*

ISSUE: ***RESIDENTIAL HEALTH CARE FOR HIVIAIDS PATIENTS***

BACKGROUND/DISCUSSION:

A residential health care facility is an establishment which serves as a substitute for the resident's own home. It furnishes food, shelter, health care monitoring, and personal care to adults. These facilities are generally designed to provide care and services to a frail elderly population. There is no data available as to the number of HIV/AIDS residents in residential health care; however, anecdotal information suggests there are not many.

Residential health care provides a protected and safe living environment. Its cost is less than nursing home care for individuals who require only a minimal amount of personal care each day. These facilities constitute a controlled living environment with check-in-out procedures, specific meal times, and health monitoring. This may be too restrictive for people accustomed to totally independent living and the needs of active young adults or HIV/AIDS residents may be difficult to integrate into these facilities.

The facilities are licensed and monitored by the Department of Health. State licensure requires residents to be 18 years of age or older. This requirement prohibits families with young children from residing in residential health care facilities. Family units may therefore have to be divided. Additionally, operators are required by licensure to maintain a homogeneous population and the mixing of frail elderly and the HIV/AIDS population may not be feasible. It is possible, however, to structure these facilities to the needs of the residents and the services they require.

Moreover, the fee paid by Supplemental Security Income reimbursement is only $16.47 per day, including the personal needs allowance. This is not adequate to meet the special health and psychosocial needs of HIV/AIDS residents. Education will be needed for both providers and residents if HIV/AIDS patients are to be successfully integrated into these facilities.

RECOMMENDATION:

- *Opportunities for HIV/AIDS admission in mainstream residential health care facilities should be expanded.*

IMPLEMENTATION STRATEGY:

- *The state should mandate integration of HIV/AIDS residents into existing residential health care facilities.*
- *The state should expand the development of residential health care facilities based on the needs and functional ability of patients.*
- *The state should expand licensure requirements to allow residents to be under 18 years of age in order to include parents with children.*
- *The state should mandate ongoing HIV/AIDS education for all residential health care operators and staff, as a requirement for licensure or certification.*
- *The state should take the lead in a discussion with the Social Security Administration about Security Income reimbursement for residential health care facilities - which is only $16.47 per day - an amount inadequate to meet the special needs of HIV/AIDS residents.*
- *The state should reallocate funds which provide shelter in motels and hotels, to provide apartments and single room occupancy living quarters to individuals.*

ISSUE: ***LONG-TERM CARE***

BACKGROUND/DISCUSSION:

AIDS can be a very demanding illness in terms of the ongoing care and treatment that is required; for some patients, institutional long-term care may be more appropriate, less costly, and more efficiently provided than either acute care or professional home health care.

Long-term care facilities provide nursing care and supportive services to people with functional impairments due to chronic and frequently degenerative physical or cognitive disorders. Long-term care facilities typically admit both long-stay patients and those who require only a short convalescent stay. Some long-term care facilities have developed "specialized" or "subacute" care programs to meet the technically complex needs of certain types of patients, including those with HIV/AIDS.

In fact, nursing homes have a long tradition of caring for patients whose symptomatology is similar to that of many AIDS patients: dementia, wasting syndrome leading to physical frailty, and neurological deficits. Specialized units for AIDS patients, staffed with clinical experts in the treament of AIDS, would ensure high-quality care.

Nursing homes could also admit AIDS patients on a short-term basis to provide a period of respite for families in need of a break from caring for an AIDS patient living at home but in need of more supervision that can be supplied by a home health agency.

It should be noted that AIDS patients who are ill enough to require skilled nursing care and to therefore qualify for admission to a long-term care facility tend to have very unstable medical conditions. They may die or revert to needing acute care within a short time before or after admission to the long-term care facility. Alternatively, their health may improve so that they no longer require institutionalization. This places a greater burden on admissions coordinators and discharge planners in nursing homes.

Moreover, many AIDS patients require ongoing medical care and services that are not provided in geriatric long-term care facilities, since the social and developmental needs of many patients with AIDS are distinctly different from those of the geriatric long-term care population. Licensure requirements may need to be modified so that treatments commonly needed by AIDS patients (e.g., drug counseling and blood transfusions for anemia) can be offered in the nursing home setting.

Long-term care facilities may not be equipped to accommodate patients with active drug addiction problems. If a patient is an active drug user and does not choose to undergo treatment (e.g., methadone therapy), it may be difficult to manage the patient and at the same time to maintain order in the facility. Moreover, as the population of AIDS patients in need of nursing home care increases, it may become more difficult for facilities to recruit additional nursing staff who have the interest in, and expertise for, working on an AIDS unit.

AIDS patients cannot be transferred to long-term care facilities until they have a Medicaid number to ensure payment. There are delays in the eligibility review process for Medicaid. Delays are occurring both at the level of the referring hospitals' social service departments and at some county Medicaid District Offices where the requests are processed.

AIDS patients may refuse admission to long-term care facilities if they are located in remote, inaccessible areas of the state. They may not be willing to leave the familiarity of their hometowns and ties for the unknown, isolated environment that the long-term care facility sometimes represents.

RECOMMENDATION:

- *The state should encourage the development of, and eliminate obstacles to, access to long-term care facilities open to HIV/AIDS patients.*

IMPLEMENTATION STRATEGY:

- *AIDS patients should be mainstre[illegible]ed in long-term care facilities and level of functional capability should be the basis of a[illegible]ssion.*
- *Long-term care facilities should be located in areas of high HIV/AIDS incidence, so that they are easily accessible.*
- *Licensure requirements should be modified when necessary, to reflect the needs of HIV/AIDS patients.*
- *Long-term care facilities should provide for those social and developmental needs of HIV/AIDS patients which are distinctly different from those of the geriatric population, such as substance abuse treatment and specific program for the management of active drug users who do not choose to undergo drug treatment.*
- *The state should develop a process for accelerating the Medicaid review process, which currently prevents HIV/AIDS patients from being admitted until they have acquired a Medicaid number assuring payment.*

ISSUE: *HOSPICE CARE*

BACKGROUND/DISCUSSION:

Hospice care is an approach to treatment which recognizes that the impending death of an individual warrants a change in focus from curative to palliative care. The goal of hospice care is to help terminally ill individuals continue life as normally as possible while remaining primarily in the home environment. A hospice uses an interdisciplinary approach to deliver medical, social, psychological, emotional, and spiritual services to make the dying individual as physically and emotionally comfortable as possible.

Hospice services, which include supportive services for family, friends, and significant others, are typically available 24 hours a day. Hospice care is generally recommended when a patient is expected to die within six to 12 months. When a patient can no longer be cared for at home, or when family caregivers require a period of respite, the hospice program usually makes arrangements for the patient to be transferred to an inpatient setting such as a hospital or nursing home.

Generally a home and the availability of a caregiving family member or friend are necessary for the delivery of home-based hospice services; therefore, the program is inappropriate for the many homeless AIDS/HIV-infected individuals, or for those who may have been abandoned by their support systems.

There are inherent problems in hospice care. HIV/AIDS-infected individuals may not be willing to accept a terminal diagnosis and palliative as opposed to curative care. Additionally, physicians are sometimes reluctant to put a six-month time limit on the life of an AIDS patient, whose health status may improve or worsen in an unpredictable manner.

RECOMMENDATION:

- *Hospice care should be made more accessible and available to all who require it.*

IMPLEMENTATION STRATEGY:

- *Hospice care should be available in congregate living areas.*
- *The availability of a caregiving family member or friend should not be a necessary eligibility requirement for home-based hospice services, nor should the six to 12-month life-expectancy limit be imposed as a condition for hospice care.*

ISSUE: SUBSTANCE ABUSE

BACKGROUND/DISCUSSION:

(For the purposes of this plan, substance abuse is broadly defined to include heroin, cocaine, crack cocaine, other addictive drugs, and alcohol.)

The New Jersey HIV/AIDS epidemic is unique in the nation because nearly 60% of its 10,000 cumulative AIDS cases are related to intravenous drug use; it is, therefore, the state's primary mode of HIV transmission. Of the estimated 50,000 regular intravenous drug users (IVDUs) in the state (at least twice that number are occasional heroin users), approximately 6,000 are currently in treatment. An estimated 50% of IVDUs in the state's larger cities, including Newark and Jersey City, are HIV infected. A majority of the 31,217 adults incarcerated in New Jersey's correctional system are IVDUs, and HIV/AIDS has hit this particular population very hard.

Poverty, discrimination and rootlessness make drug users one of the most difficult populations to reach. Most IVDUs are heterosexual and sexually active; their sexual partners, many of whom are women of childbearing age, are also at risk. Nationally, 49% of women with AIDS have contracted it through heterosexual transmission; most of the children with AIDS in New Jersey became infected, directly or indirectly, through a drug-using parent. It should also be noted that in New Jersey minority women are disproportionately represented among women with HIV/AIDS.

Since 1982, New Jersey has consistently had more than twice the percentage of female AIDS cases when compared to the United States. This is attributable to female transmission from their own intravenous drug abuse - which accounts for 1,295 cases and is 64% of adult/adolescent female cases - and to women contracting the virus from their male sexual I.V. drug-abusing partners (602 cases or 30% of all female cases).

Among I.V. drug users, the utilization and sharing of contaminated "works" - needles and syringes - frequently leads to HIV infection, but New Jersey is one of only 11 states in which needles and syringes cannot be purchased over the counter. The legalization of over-the-counter purchase would allow drug treatment programs to purchase needles and syringes in bulk supply for distribution to I.V. drug abusers.

Effective drug treatment in New Jersey is synonymous with AIDS prevention. Drug treatment is a right and its denial constitutes a withholding of life-saving measures. Moreover, the total cost of drug treatment is significantly less than the cost of AIDS care. Outpatient methadone treatment, for example, costs between $2,200 and $3,000 per year. The costs of residential treatment range from $14,000 to $20,000 per year. On the other hand, the average lifetime cost of treating a person with AIDS is far greater than $60,000.

Despite these financial realities, the quality and quantity of drug treatment available in urban areas of the state is inadequate to meet current needs. In fact, since 1981, New Jersey's drug treatment facilities have been forced to charge fees due to cutbacks in funding. This has been an additional deterrent to users seeking treatment. The state's capacity to identify, assess and treat substance abusers must be increased. This can be done in a variety of ways.

Using existing facilities, the state could increase by 2,000 the number of methadone maintenance slots in existing major metropolitan programs. This could be accomplished within three months by expanding operating hours and hiring additional staff. Without copayment for indigents, the cost for this process would be about $6,000,000. This could be substantially met by initiation of a Medicaid reimbursement schedule that reflects the actual costs of treatment, and the institution of reimbursement from DEA.

It is also currently estimated that 1,000 patients are in need of intensive out-patient cocaine treatment in existing out-patient methadone and drug-free programs. Some of these patients could be enrolled in both methadone and intensive cocaine treatment. The cost is estimated at $2,000,000, much of which should be reimbursable. There would be a time frame of approximately three to six months for implementation .

Women-specific programming is very badly needed. It could be instituted in methadone and residential programs to provide culturally sensitive educational and therapeutic intervention as well as medical referral and linkage to needed social services. Out-patient programs could provide enhanced child-care services if space permits. The time frame for implementation of this process would be approximately three months, with a cost of approximately $1,000,000.

To cite one example of particular importance, there are simply not enough services available for drug treatment of pregnant women. In 1989, a joint Maternal Child Health Service/Division of Alcohol and Drug Abuse initiative resulted in the setting aside of beds in ten residential facilities in the state for the treatment of alcohol and/or drug addiction in pregnant women. In 1990 one outpatient drug treatment facility for pregnant women was set up with a grant from MCH, and three more clinics should be in operation by January 1, 1991. These services will not only help women reduce their chances of acquiring HIV infection, through drug injection or sexual activity for the purpose of obtaining, or under the influence of, alcohol and drugs, but will also reduce the occurrence of physical and emotional problems in hildren due to fetal exposure to HIV, alcohol, and drugs. It is clear that many more services are needed, since only about 200 women can presently be treated. One possibility might be for Medicaid to expand HealthStart codes to include a reimbursement code, as part of pregnancy services, for drug treatment and a new code for HIV testing and counseling/education.

Given the linkage of the HIV/AIDS epidemic in New Jersey with drug abuse, it would be advantageous for HIV testing and counseling as well as early intervention to be available on-site as an option for all methadone patients. The means of providing this service would vary depending on the program's size, needed space, reimbursement mechanisms, and availability of community health centers or hospitals that could co-locate services. Funding and time frames would therefore vary from site to site. Ideally, HIV intervention ought to be included in the context of primary health care.

It would also be advantageous to integrate substance abuse services into other facilities. Existing major infectious disease clinics and early intervention programs in hospitals and community health centers could have their own or co-located ambulatory substance abuse programs with methadone capacity, which would serve their patients or the parents of pediatric patients. Funding and time frames would again vary from site to site. It would also be beneficial for all programs in the Department of Health that serve high-risk families (TB, STD, Family Planning, Prenatal, MIH programs etc.), to have a substance abuse/HIV specialist on staff to provide staff education, patient consultation, assessment and referral.

This service coordination could also be enhanced by the creation of regional family services centers providing family-centered case management. These are discussed in more detail elsewhere in this plan. At such a center, every patient and family would be assigned a case manager. This system of case management would replace the multiple case managers currently attached to various projects, and would facilitate development of the county-by-county system suggested by the Community Advisory Group. Mental health services and support groups linked effectively to drug treatment and other support services are currently in short supply. There is also a lack of coordinated adult and pediatric primary care services for all family members, as well as TB and STD services and reimbursed family planning. Family service centers could help to remedy these deficiencies.

Housing for this population is discussed elsewhere in this plan.

RECOMMENDATIONS:

- *Substance abuse treatment - both inpatient and outpatient - should be available on demand.*
- *Legislation should be enacted to ensure that the full range of drug treatment is available for all who require the services.*
- *Demonstration projects should be established to test the effectiveness of needle- and syringe-exchange programs.*
- *Legislation should be enacted to allow for the over-the-counter purchase of needles and syringes.*
- *The State should create culturally sensitive and appropriate substance abuse programs designed to meet the unique needs of minority women.*

IMPLEMENTATION STRATEGY:

- *The state should expand inpatient substance abuse treatment programs for both adults and adolescents.*
- *The State Legislature should also appropriate $15 million to develop need outpatient drug-free, methadone maintenance and residential drug treatment slots and rehabilitation facilities for intravenous drug and other substance abusers. The Department of Health should assist in the development and adoption of any necessary and appropriate regulations or legislation.*
- *The state should fund expanded substance abuse services for pregnant woman in residential facilities, and increased outreach for women and adolescents.*
- *The state should encourage the development of "drop-in" substance abuse treatment for those who wish to decrease their drug use over the long term, but who are not ready for short-term detoxification programs.*
- *The state should consider the creation of regionally-based comprehensive family service centers providing family-based case management.*
- *Joint ventures should be pursued to link services such as medical and social day care, respite care, shelter-provision, food vans, and clothing exchanges with drug treatment.*
- *The state should review existing regulations for both medical and third-party reimbursement for drug treatment services.*

- *Local general assistance programs should also be authorized to reimburse the cost of drug treatment.*

- *Medicaid reimbursement levels should be adjusted to cover the actual cost of drug treatment, regardless of the source of funding, until a larger, more comprehensive policy is developed.*

- *Comprehensive drug treatment coverage should be included in all new private medical insurance plans.*

- *Incentives should be developed and implemented to increase the medical, nursing and counseling personnel available for drug treatment.*

- *Executive and legislative leadership will be required to deal with not-in-my-backyard syndrome (NIMBY) in New Jersey.*

- *The Department of Health should develop needle- and syringe-exchange demonstration projects at selected geographic sites of high HIV prevalence in New Jersey. Access for successful programming, including expanded hours for obtaining services, should be included in any proposed demonstration project. An educational component, including education regarding proper use and distribution of condoms, as well as an offer of voluntary HIV testing, should also be incorporated. Serosurveys for research purposes could be conducted on returned needles and syringes to determine incidence.*

ISSUE: ***GENERAL HOUSING***

BACKGROUND/DISCUSSION:

As the number of persons with HIV/AIDS - many of them socially disenfranchised and/or homeless - increases in New Jersey a serious attempt at providing adequate housing with minimal financial and social cost must be found. The goal of the State plan is to meet the needs of persons with HIV/AIDS by using mainstream housing whenever possible to maintain the cohesiveness of the family and the community.

The HIV-infected in New Jersey badly need housing at all levels, but particularly that providing intermediate levels of care such as nursing homes, residential health care facilities, transitional housing, boarding homes and congregate care facilities. This broad spectrum of housing options must be exploited.

It is also clear that appropriate housing must be provided for those who need minimal medical supervision and who would refer an environment with minimal structure. Finally, the state plan must take into consideration the needs of those who can live on their own without either medical or social supervision. Any housing plan developed must be flexible and able to meet the diverse needs of all in the community.

The issues that must be discussed and resolved before a comprehensive plan can be implemented and appropriate housing services provided include financing and reimbursement, coordination of the various executive agencies that oversee housing, and removal of the barriers of discrimination.

One of the most serious obstacles which the state must address is the lack of coordination of housing regulations and policies among the Department of Health, the Department of Human Services, and the Department of Community Affairs.

Resources that are potentially available but currently underutilized by HIV/AIDS patients are residential health care facilities (RHCFs) and apartments. Such facilities could be readily used to provide for the residential needs of HIV-infected patients with minimal economic impact on the health care system. Residential health care facilities are discussed elsewhere. Apartments available to the general public could be used the for placement of homeless families and individuals. Currently indigent/homeless persons with AIDS/HIV infection are the responsibility of public welfare agencies. These agencies are required by the state to provide "emergency assistance" for an unlimited period of time in the form of per diem payments of any amount that is necessary (as much as $50 to $80 per night) for hotel or motel rooms. Revenue for emergency assistance is provided by the state's Division of Public Welfare (75%) and by each municipality (25%). In the city of Newark alone, there are currently as many as 180 general assistance recipients believed to have HIV/AIDS housed in hotel or motel rooms. This number has nearly tripled since May 1989. Clearly, emergency assistance resources currently used to house HIV/AIDS patients in hotels and motels would be more prudently expended on residential health care, rent subsidies, or on appropriate supportive services.

Persons with HIV/AIDS in substance abuse recovery and their families, cannot obtain decent affordable housing in a drug- and alcohol-free environment near the resources they need. The state should look into the possibility of using HUD/state/local housing developments as "Substance Abuse Free Housing Zones." The tenants of these developments would be empowered to operate and maintain their own housing units with the aid of a residential substance abuse treatment provider. Residents would pay for individual apartments or rooms on a sliding scale based on income from employment, SSI, and welfare. They would be required to agree to an access-controlled, monitored environment free of chemical abuse.

Due in part to financing issues and discrimination, there is currently a lack of all such facilities in New Jersey. The services that are provided are fragmented. The lack of coordinated services for HIV-infected persons may be keeping them in inappropriate settings such as an acute care hospital, or in one of the few highly reimbursed nursing homes that accepts AIDS patients. The level of care in either type of facility is expensive, and sometimes clinically and socially inappropriate.

The benefits of using funding to subsidize residential health care, and to pay rents and other support services would result in better living conditions, the greater availability of health services either in the residential health care facilities or through home health care agencies, and long-term cost savings to the general public.

RECOMMENDATION:

- *Housing should be developed to meet the diverse needs of the HIV/AIDS population, including mainstream, private sector apartments, boarding house, and group homes designated for HIV/AIDS patients.*

IMPLEMENTATION STRATEGY:

- *The state should revise regulatory barriers between departments which hinder access to housing and the provision of needed health services in congregate living situations.*
- *The state must vigorously enforce laws and regulations which bar discrimination in housing.*
- *The state should encourage the development of innovative types of housing for the HIV/AIDS population.*

RECOMMENDATION:

Needs Assessment

- *The state should obtain information to assess the need for housing for HIV-infected persons.*

IMPLEMENTATION STRATEGY:

- *The state should initiate a review and a needs assesment of existing residential care facilities, particularly in regard to accessibility and funding of such facilities, in or near affected communities. This review would include an examination of the need for emergency housing for HIV-positives not eligible for current programs, and the need for supported housing.*

- *The state should review previous studies and other available material on improving housing and residential care. These materials suggest that substantial improvements in the provision of services are possible without an expenditure of large amounts of new revenue.*

RECOMMENDATION:

Housing Information and Service Coordination

- *The state should take steps to coordinate information and services on housing at the state level.*

IMPLEMENTATION STRATEGY:

- *The State should centralize the information available within state departments on housing, licensing, regulations and Certificates of Need, so that persons requesting information need make only one visit, instead of multiple visits to different Departments.*

- *The state should concentrate in one place the responsibility for licensing and overseeing services for persons with AIDS (PWAs) in residential facilities. The final authority to approve new facilities and ongoing inspection should be located in one agency with a cooperative relationship with the other traditionally responsible agencies.*

- *The state should encourage the Department of Community Affairs' Bureau of Housing Services to continue the dialogue recently initiated with the Departments of Health and Human Services on comprehensive planning for the homeless. The Department should continue to explore the availability of resources, such as federal McKinney funding, for housing initiatives.*

- *The state should implement a mechanism to encourage innovative solutions to housing problems under the licensing standards of the Department of Community Affairs, Department of Human Services and the Department of Health; these variations should be monitored for effectiveness. This mechanism could then be expanded to other populations with residential care needs.*

RECOMMENDATION:

Financing

- *The state should work toward the provision of housing for HIV-infected persons through appropriate funding or other financial initiatives.*

- *Appropriate state departments and New Jersey's congressional delegation should lobby for housing for persons with HIV/AIDS. This includes lobbying for funding of the McDermott bill.*

IMPLEMENTATION STRATEGY:

- *The state should critically examine the discontinuities in funding of residential services for PWAs; look at permitting state funding for appropriate shelters and for maintaining HIV-positive persons at the appropriate level of care (e.g. increase the state portion of the SSI grant).*

- *The HIV/AIDS population should be given priority in the granting of Section 8 housing certificate.*

RECOMMENDATION:

Human Rights

- *The state should ensure that access to appropriate housing for persons infected with HIV is not barred because of human rights violations.*

IMPLEMENTATION STRATEGY:

- *The state should pursue greater access to existing facilities for HIV positive persons by enforcing the antidiscrimination requirements of state and federal law; in the meantime, existing services, such as nursing home care, should be fully and appropriately utilized.*

- *The state should initiate dialogue with nursing homes, and appropriate associations, on the existing regulations that prohibit refusal to accept patients based solely on a diagnosis of HIV positive or AIDS.*

- *The state should enforce the existing state and federal laws against discrimination on the basis of HIV disease.*

GENERAL HOUSING - GENERAL RECOMMENDATION:

- *The state should initiate these recommendations and suggested mechanisms for the HIV/AIDS population as a pilot project, which then can be utilized for other groups with similar housing issues.*

ISSUE: ***MENTAL HEALTH***

BACKGROUND/DISCUSSION:

Discrimination against the mentally ill is not a new phenomenon, but the coming of AIDS - some of whose manifestations are neurological and psychological - has created yet another group that is encountering difficulties in accessing medical care and treatment.

In order to ameliorate this problem, appropriate HIV/AIDS education, developed by the Division of Mental Health and Hospitals of the Department of Human Services, is needed for both staff and patients in the state's public and private mental health facilities. "Special needs clients," as defined by the Division of Mental Health and Hospitals, need to be integrated into the education process; through policies developed jointly by the DOH's Division of AIDS Prevention and Control and the Division of Mental Health and Hospitals. Particular attention should be given to both clients and operators of congregate living facilities.

Better information-dissemination and service-planning mechanisms for mentally ill HIV/AIDS patients are also required. In particular, the Division of Mental Health and the Division of AIDS need to examine the Certificate of Need process as a means of implementing changes in the delivery of mental health services to HIV/AIDS patients.

RECOMMENDATION:

- *Mental health services should be expanded to treat the specific needs of HIV/AIDS patients, such as organic brain syndrome and dementia.*
- *All direct mental health service provides should include ongoing HIV/AIDS education.*
- *In order to provide services to all groups including HIV/AIDS, the state must first coordinate mental health services with local community-based organizations and provide for sufficient reimbursement.*
- *The state should encourage the appropriate expansion of mental health services.*
- *The state should require the ongoing HIV/AIDS education of mental health services providers as a requirement for facility and professional licensure or certification. (There is a minority opinion that, although health care professionals should receive necessary HIV/AIDS education, it should not be a requirement for licensing certification.)*

ISSUE: ***HOME HEALTH SERVICES***

BACKGROUND/DISCUSSION:

Home health providers supply the needed services to those who are HIV/AIDS infected which enable them to remain in their community and with their family. Over the years home health service organizations have provided communities with needed, coordinated and integrated services for all patients.

There are however, several problems confronting New Jersey home health service providers in regard to HIV/AIDS. Staffing is a major concern of these agencies as well as that of most health care providers in New Jersey and throughout the nation. The provision of specific services to individuals with HIV/AIDS needs to be expanded to meet the growing demand of those presently unable to obtain them. The availability of registered nurses and nurse practitioners and the licensing of physicians' assistants would go a long way toward helping meet this need. In some cases, the services of physicians may be required; therefore, a physician reimbursement mechanism will be required.

To encourage the hiring of more home health care staff a career ladder mechanism for those who providing basic "homemaking" services such as cooking and cleaning might be considered. There is also a need for a training program for all staff in all agencies to reduce anxiety about providing services to individuals with HIV/AIDS.

The use of volunteers functioning under the auspices of home health care service providers would be a good strategy. Patterned on the current "buddy" system, volunteers could considerably augment the services of these providers. A statewide standardized training and education program would have to be developed and implemented.

Home health providers need to provide services to congregate living facilities and reimbursement should be available for these services. Also, there is a need to modify the regulation which prohibits the use of home health services within the confines of some settings.

RECOMMENDATION:

- *The state should encourage the expansion of home health care services for HIV/AIDS patients.*

IMPLEMENTATION STRATEGY:

- *Home health care can be increased through the development of volunteer "buddy" systems associated with home health agencies. Standardized training requirements for those volunteers must be established.*

- *A career ladder based on experience should be created for home health care providers. These providers should receive HIV/AIDS education to reduce their anxiety about providing services to this population.*

- *Physician reimbursement should be established for home visits.*

ISSUE: ***MANAGED CARE***

BACKGROUND/DISCUSSION:

One of the characteristics of HIV/AIDS patients which makes them difficult to treat effectively is the rapidity with which their medical condition changes. The current health care delivery system concentrates too much on the place of treatment and too little on the unique needs of each HIV/AIDS patient. Patients for whom a well-developed referral network with accompanying payment streams does not exist will get the least consistent care in the present system. This is a major problem to patients with chronic diseases; for an HIV/AIDS patient who may lurch from one acute episode to the next, it could be fatal.

A managed-care approach seems to be the best way to deliver care to HIV/AIDS patient. It is difficult to administer at first, but over time would improve access not only to hospital services, but to other, customarily unaddressed needs such as housing, long-term social services, drug treatment services, and hospice services, among others.

Currently, the only steady funding streams for indigent patients are the Medicaid program and the Uncompensated Care Trust Fund. These systems have several drawbacks. They can be very limited in the scope of services they provide, and they are facility-oriented rather than client-oriented. Further, the Trust Fund encourages patients to use the most intensive health care, even though it may be the least appropriate and most costly.

This is a propitious time to capitalize on the dynamic health insurance/state budget issues and establish a managed-care approach to HIV/AIDS. The Garden State Health Plan is already operated by the Department of Human Services, and their experience with rate-setting and actuarial modeling would be helpful in determining the costs of the program. A comparison of the amount of current health care expenditures in acute, long-term, and home health services for HIV/AIDS patients could be contrasted to the projected cost of benefits delivered by the managed-care plan. The key to establishing a successful program would be the accurate identification of the population to be served, and a use of a one-time

comprehensive eligibility and medical evaluation of the patient.

Under this approach, all of the participants would have access, through one case manager, to a myriad of services, both medical and non-medical. For one fixed rate--determined by actuarial analysis--Medicaid could pay for hospital care, long-term care, Residential Health Care Facilities (RHCF) care, purely residential accommodations, medical day care, social counseling, and prophylactic treatment in a clinic setting. This approach would yield a cost savings by getting patients to the lowest appropriate level of care at the earliest possible moment, and by preventing unnecessary acute episodes due to the lack of prophylactic- or maintenance-level care.

Licensure standards for involved facilities must reflect the variety of modalities through which care would be provided. In fact, there would probably be services provided which are not at this time even regulated by the Department of Health. These licensure issues need not present insurmountable obstacles.

The single most important factor to be addressed is Medicaid's participation in the program. Medicaid has already broken ground in projects such as the home health waiver demonstration project, and, as stated previously, has managed-care experience with the Garden State Health Plan. Along with finding a provider to commit to this plan, a state amendment to the Medicaid program and the development of a capitation rate would be the most significant milestones for the project. Working out a single rate would in the long run actually be easier for Medicaid to administer because auditing the plan would be much less complicated. In addition to other advantages, it is important to note that since Medicaid would be a major payer, a large portion of the cost- about 50%-- would be assumed by the federal government.

This sort of project lends itself well to the kind of working group that would meet the following criteria:

1. *The physical plant needed to serve as a core facility is or can be developed.*
2. *A joint venture by several participating community-based facilities.*
3. *Familiarity with the Medicaid program and other major health care payers.*
4. *Established links to the community, which will assist in utilizing resources without duplication.*

Given the variety of potential payers this project could actually result in cost savings, while improving the quality and appropriateness of care services.

RECOMMENDATION:

- *A comprehensive system of managed care should be developed.*

IMPLEMENTATION STRATEGY:

- *The State should take the lead in encouraging managed care by creating a demonstration project with a negotiated system and in a designated area.*

ISSUE: ***RESPITE CARE***

BACKGROUND/DISCUSSION:

Opportunities for respite care should be expanded to maximize family involvement in caring for individuals with HIV/AIDS. There is a need to expand availability of respite care so that those individuals - especially maternal care givers caring for their children - or even their children's children - can continue to care for their families and not become isolated or unwilling participants in the care of friends and family.

There is also a need for improved access to respite care must be improved for people of lesser financial means who need the service to fulfill job obligations and to maintain normal lives.

Volunteers can be a major source of respite care, if they are carefully trained, tracked and monitored and given reasonable expectations of the work involved.

RECOMMENDATION:

- *Opportunities for respite care should be expanded.*

IMPLEMENTATION STRATEGY:

- *The state should expand the availability of respite care.*
- *Access to respite care must be improved for people of lesser financial means.*
- *Volunteers can be a major source of respite care, if they are carefully trained, tracked and monitored.*

ISSUE: ***DENTAL SERVICES***

BACKGROUND/DISCUSSION:

The lack of dental services for both adults and children with AIDS or HIV infection has been and remains major concern all over the state. The availability of this service to these patients is concentrated in the hands of a small number of practitioners. There is no area in New Jersey that could not benefit from more dental services for HIV/AIDS patients.

There is considerable evidence of individuals who call or go to dentists only to be refused treatment or be sent to other treatment centers such as the UMDNJ program co-funded by the New Jersey State Department of Health and other sources. In one such case, a man with AIDS contacted 27 dentists and could not get an appointment because of his condition. This is particularly worrisome because the oral infections that HIV/AIDS patients often develop are not only uncomfortable but life-threatening, and require immediate attention.

To meet the growing need dental clinics, especially community based, need be established in strategic locations. The Advanced Education in General Dentistry program has proved extremely useful and could possibly be expanded to serve persons with HIV/AIDS. It trains dentistry residents to provide services to such underserved populations as migrant workers.

Currently medical and other reimbursement rates provide insufficient incentive to dentists to treat persons with no other financial resources. The requirement of preapproval of procedures also hinders access to services. Delay in service can result in a serious infection.

RECOMMENDATIONS:

- *Dental services should be made available to both adults and children with AIDS or HIV infection.*
- *Medicaid must continue to cover dental services, and reimburse for them at a reasonable rate.*

IMPLEMENTATION STRATEGY:

- *The state should require that dental service providers use OSHA guidelines in the provision of services in all clinics.*
- *The state should review for appropriateness the current rate of Medicaid reimbursement for dental services.*
- *Insurer's provisions for reimbursement for dental services for should be expedited.*
- *Dental clinics should be established in strategic locations.*
- *Community-based dental services provided, by local dentists, should be expanded*
- *The Advanced Education in General Dentistry (AEGD) program, which trains residents in dentistry should be expanded to treat additional underserved populations.*
- *The state should require the ongoing HIV/AIDS education of dental service providers as a requirement for facility and professional licensure or certification. (There is a minority opinion that, although health care professionals should receive necessary HIV/AIDS education, it should not be a requirement for licensing certification.)*

ISSUE: ***INCARCERATED POPULATIONS***

BACKGROUND/DISCUSSION:

The incidence of HIV/AIDS in the incarcerated population in New Jersey is among the highest in the United States. In New Jersey the problem is compounded by substance abuse and affects their families and communities. They must rely on their custodians to provide all services. It is therefore imperative that the Department of Corrections in conjunction with the State Department of Health establishes policy and plans an HIV/AIDS program for all inmates.

One of the most important tasks in formulating such a program is determining whether or not the Department of Corrections can impose standards on local correctional facilities. A mechanism must be developed by the state that will create a uniform standard of care applicable to all inmates in the correctional system. All medical treatments for HIV/AIDS available to the non-incarcerated must also be available to inmates, which is not presently the case. Necessary supportive social services should also be made available to them while incarcerated, upon release and while under supervision in the community.

High-risk populations such as those in prisons are especially vulnerable to HIV/AIDS, and at present there is no mechanism encouraging high-risk prison populations to test voluntarily in state and local prisons. The issue of confidentiality of results is particularly important for this population in order to protect them from discrimination and physical harm. At present there appears to be no need for universal mandatory testing. Finally, the question of whether or not condoms should be distributed upon request needs to be studied.

There is also growing concern in New Jersey over the lack of education being provided to the spouses of inmates. There are few educational materials available and only marginal outreach is being provided. The New Jersey Association on Corrections has a special outreach to women which might be investigated as a model to expand HIV/AIDS efforts to women in general. This program supplies trained women to go out into the community and educate women either one-on-one or in groups, depending on what is best for the particular community.

A diagnosis of HIV/AIDS is, in the minds of many, a death sentence. But hope needs to be maintained. As time passes more and more experimental medications and treatments are appearing. The State must examine current rules and regulations that currently prohibit inmates from participating in clinical trials and experimental protocols of these medications and therapies in state and local prisons, and amended for this purpose.

RECOMMENDATION:

Provision of Service

- *Opportunities for testing and treatment of HIV/AIDS-infected incarcerated persons must be expanded to serve the needs of this population.*

IMPLEMENTATION STRATEGY:

- *All medical treatments for HIV/AIDS, which are available to the non- incarcerated, should be made available to those who are incarcerated. As a matter of principal, incarcerated persons should be allowed to retain all medications at the time of incarceration.*
- *Voluntary testing should be made available to all incarcerated persons.*
- *All testing should be accompanied by pre- and post-test counseling in correctional facilities.*
- *No mandatory testing should take place in any state or local correctional facility.*
- *A mechanism which will encourage high-risk incarcerated populations to test voluntarily in correctional facilities.*
- *Policies and procedures which assure confidentiality in state and local prisons should be mandated and implemented.*
- *All persons who qualify should be allowed to participate in experimental protocols in correctional facilities, and regulations forbidding participation should be amended.*
- *Additional social services should be made available to those who are HIV/AIDS infected.*
- *Condoms should be distributed to incarcerated persons upon request.*
- *Family members of HIV/AIDS-infected persons should be allowed greater visiting privileges.*
- *The Department of Correction should utilize counseling and testing personnel from the Department of Health and local health agencies.*

RECOMMENDATION:

Access to Services

- *The state should ensure that prisoners receive the same services that are available to the general population.*

IMPLEMENTATION STRATEGY:

- *The state should pursue the voluntary entry of inmates into clinical trials with experimental drugs. The Department of Corrections has received approval from the Attorney General's Office which authorizes physicians to use "innovative or experimental treatment" as long as the inmate wishes to receive it and "in the physician's opinion it benefits the inmate."*

- *The state should institute broad, voluntary testing of inmates, with accompanying treatment and prophylaxis. The Department of Corrections has drafted policy revisions to implement this change and is awaiting administrative approval and funding. Preliminary estimates indicate that an annual cost of $11 million would be incurred if 60% of the base population plus new admissions in year one were tessted and treated. The succeeding years' costs would hold at about the same level because of the need for repeat testing and CD4 counts, and the need for AZT, Pneumocystis carinii prophylaxis and other available therapies.*

- *The state should establish an intermediate level nursing care facility for the correctional population, to include incarcerated persons who's medical condition or security status preclude housing in the general population. This will require some "set-up" costs, but in the long run inmates would be moved out of an acute care setting to the nursing care level which is more cost effective.*

RECOMMENDATION:

Coordination of Services

- *The state should ensure that standardized, coordinated services are available, and provided to all correctional populations.*

IMPLEMENTATION STRATEGY:

- *The state should pursue resolution of the Department of Corrections' authority over municipal and county jails, and initiate or continue dialogue to standardize testing, counseling and treatment of HIV-infected inmates at all facilities.*

- *The state should coordinate an educational program between the Departments of Corrections and Health to be given to all inmates upon admission and discharge.*

- *The state should coordinate efforts of the Departments of Health and Corrections to train and counsel inmates and their families in HIV awareness. A program to select, train and utilize inmates as certified HIV counselors could be implemented. This group of inmates could be used in educational programs for juveniles within the Corrections system, and their expertise could prepare them for employment opportunities upon release.*

- *The state should review the procedures for medical clemency and resentencing, and ensure standardization and application of those procedures.*

RECOMMENDATION:

Human Rights

- *The state should ensure that the human rights of prisoners are not violated.*

IMPLEMENTATION STRATEGY:

- *The state should initiate review of procedures for maintaining confidentiality of inmate test results and records, and improve procedures where necessary.*
- *The state should ensure that testing for HIV is done with informed consent, and that counseling for all inmates tested is provided.*

ISSUE: ***HIV/AIDS DESIGNATED UNITS IN ACUTE CARE SETTINGS***

BACKGROUND/DISCUSSION:

In the past, there was a question whether or not specific HIV/AIDS - designated units in hospitals should be developed. The questions raised by this issue are specific to the area where the hospital is located, the size of the hospital, and the number of HIV/AIDS patients that it would treat.

If the hospital is small, a designated unit may not be indicated; on the contrary, it may be a hindrance to services and lead to difficulties in maintaining the confidentiality of HIV/AIDS patients.

On the other hand, a larger hospital might benefit from such consolidated services because it would treat more HIV/AIDS patients and probably encounter fewer confidentiality problems. Indeed, a designated unit in a large hospital could prove financially and socially advantageous to both HIV/AIDS patients and the hospital itself.

In light of these considerations, the State should not set policy on hospital designated units. Instead, hospital management should decide which course would be more beneficial to their particular institution.

RECOMMENDATION:

- *Hospital managements should establish HIV/AIDS - designated units based upon need and the impact upon that particular institution.*

ISSUE: ***SUB-ACUTE IN-HOSPITAL CARE***

BACKGROUND/DISCUSSION:

If this plan had been written three years ago, its overwhelming recommendation would have been to encourage the development of in-hospital sub-acute care for persons with HIV/AIDS. Over the past two years or so, however, the situation has changed, and it is now possible to offer sub-acute services in long-term care facilities at a lower rate of reimbursement. This also allows hospital beds to be more advantageously used to treat those with acute illnesses.

Accordingly, in-hospital sub-acute care for HIV/AIDS patients should not be expanded at this time; instead, resources should be diverted to the development of other levels and methods of health care delivery, such as home health and medical day care, and nursing homes.

The state should encourage the development of appropriate methods and levels of health care delivery, and increasingly meet this need through community-based service providers.

RECOMMENDATION:

- *In-hospital care for sub-acute HIV/AIDS patients should not be expanded at this time; resources should be diverted to the development of other levels and methods of health care delivery, such as home health and medical day care, and nursing homes.*
- *A reimbursement rate should be established for patients needing less-than-acute-care services while awaiting discharge to community-based sub-acute care providers.*

IMPLEMENTATION STRATEGY:

- *The state should encourage the development of appropriate methods and levels of health care delivery, based in the community.*

ISSUE: ***SERVICES AND TREATMENT FOR HIV/AIDS-INFECTED WOMEN***

BACKGROUND/DISCUSSION:

In his October address Governor Florio made a point of recognizing the HIV/AIDS-related needs of women and the special consideration they would receive in the New Jersey HIV/AIDS Plan. These needs were attested to by one woman after another at the public meetings held in conjunction with the development of this plan. Unlike most of the rest of the United States, in New Jersey a significant number of reported HIV/AIDS cases are women. But services geared toward women that accommodate their needs have been slow to evolve, with the exception of the Women's Clinic at the University of Medicine and Dentistry of New Jersey. There is much to do.

More extensive medical services for women with clinical AIDS must be established. Recent advances in medical knowledge about HIV infection have demonstrated that there are manifestations of the disease that are unique to women. Of particular concern are gynecological complications, some of which (pelvic inflammatory disease and cervical cancer for example) can be life-threatening. The Women's HIV service at University Hospital in Newark should be expanded, and a similar clinic to serve the central and southern parts of the state should be created.

One of the chief impediments to improving services to women with HIV/AIDS is the continued use of the CDC definition of the disease. Women are paying the price of a male-model definition of HIV/AIDS which defines what treatment and services they will receive and is used by Social Security to screen for benefits. The CDC definition does not take into account the problems mentioned above that appear in women. Women are dying in New Jersey of HIV syndrome and AIDS without ever receiving a diagnosis of AIDS because their infections were woman-specific and not included as part of the CDC definition.

This male-model CDC definition for HIV/AIDS presents one other problem. Medications and treatments are consequently also based on male models, with little or no research protocols which involve women. (Please see page A-____ for a list of medical conditions suggested which may be linked to HIV infection in women.)

Currently there is a law suit filed by advocacy groups to change the definition and make it more applicable to women nationwide. The question now is whether or not the State of New Jersey should join this law suit on behalf of the women of the state.

To test for HIV infection in women and children requires extensive outreach to high-risk women to inform them about, and encourage them to use, prenatal and/or family planning services. The number of HIV-infected women being served in prenatal and family planning clinics is well below the number expected, given the results of testing of reproductive age women through the blinded study of seroprevalence in newborns. Many of the highest-risk women are not currently using either family planning or prenatal services, and community-based outreach is needed to encourage them to do so.

General outreach efforts must be linked with community-based organizations and primary care delivery. The key to successful outreach is to get women into services as soon as possible. Existing outreach teams could be expanded, with staff specializing in identifying the women most likely to be engaging in behaviors that put them at risk of HIV infection.

In order to reach women, especially in minority communities, special attention must be paid to culturally appropriate education. Support groups are a good way to reach HIV/AIDS-infected women. Currently most groups are male-oriented and few are available to women.

Finally, women also are playing a special role in this epidemic. As previously mentioned, many of them are taking care of those friends and family who are afflicted. Services such as homemaking and respite care should be made more readily available to these women who are responsible for the care of HIV/AIDS-infected family members.

RECOMMENDATION:

- *HIV/AIDS services and treatment should reflect the specific and distinct needs of women, especially with regard to coordination of service delivery to families.*

IMPLEMENTATION STRATEGY:

- *Dependant care services should be made available either in the home or at provider care sites.*
- *All ambulatory clinics should provide or be linked to OB-GYN services.*
- *Opportunities for the development of support groups for women who are HIV/AIDS infected should be expanded.*
- *Services (homemaker, respite care) should be made available to women who are responsible for the care of their HIV/AIDS-infected children or children's children.*
- *The state should encourage that all experimental protocols in New Jersey include women in their development and evaluation unless medically contra-indicated.*
- *The state should immediately pursue a change in the CDC definition of AIDS to reflect the distinctive experience of women. The state should immediately pursue action, legal and otherwise, to challenge the CDC AIDS case definition. For example, it should join the suit against the SSA, which is currently using the CDC definition erroneously as a screening mechanism.*

- *Special efforts must be made to reach women in minority communities to provide culturally appropriate education.*

- *Dependant care services must be made available in the home or at provide care sites.*

ISSUE: ***MINORITY WOMEN***

BACKGROUND/DISCUSSION:

Many minority women do not feel that they are in control of their own lives. The burdens of poverty, broken families, infant mortality, hunger and drug abuse make it difficult--if not impossible--for some women simply to get from one day to the next. The advent of AIDS, and its intertwining in New Jersey with drug abuse and other problems, has simply increased the burden. Steps must be taken to empower minority women and, in particular, to help them develop knowledge and skills which enable them to confront and resolve problems related to health care and treatment.

It has been established that men and women present differing symptoms of HIV infection, and that HIV/AIDS drugs can have varying effects depending on the sex of the patient. Moreover, there is evidence that minority men and women may react differently to a drug than do whites. To date, however, there have been very few if any minority women enrolled in clinical trials of HIV/AIDS experimental drugs. Their participation would appear to be essential in any determination of the safety and efficacy of a new drug.

RECOMMENDATIONS:

- *The state should create comprehensive health centers oriented to the specific health care needs of minority women and adequate in size and scope to cover this population.*

- *The state should create a substance-abuse program designed to meet the often unique educational, prevention and treatment needs of minority women.*

- *The state should encourage the participation of minority women in ongoing and future clinical trials of new drugs related to HIV/AIDS unless medically contra-indicated.*

IMPLEMENTATION STRATEGY:

- *These comprehensive health centers should be based in the community, and should provide a continuum of care of direct services that are culturally appropriate and sensitive, including: nutrition, maternal and infant care, HIV and drug counseling and testing, family planning, and case management.*

- *Centers should be centrally located and accessible by public transportation.*

- *Centers should provide day-care services so that women may bring their children with them.*

- *Centers should remain open into the evening to ensure access for working women.*

- *Centers should be staffed with qualified personnel who reflect the racial, ethnic and linguistic composition of the communities they serve. When appropriate, some or all of the staff should be bilingual/bicultural.*

- *The substance-abuse program should provide a continuum of in- and outpatient services. Mabon House in New York City is a successful example of such a therapeutic community, and could serve as a model.*

- *Minority women's participation in clinical drug trials should be encouraged, unless medically contra-indicated, by means of an educational campaign targeted at minority women and health care providers. The campaign should stress the potential benefits -- both personal and societal--of participation in trials.*

ISSUE: ***CASE MANAGEMENT***

BACKGROUND/DISCUSSION:

All committees involved in developing this plan recognized the imperative need to develop a workable case-management system; such a system is integral to the development of any new services and the linking of existing services. An effective case-manager system should operate on a county-by- county basis, and act as a resource to hospitals, clinics, and primary care physicians. Most importantly, it should be the patient's main contact to help him/her navigate through the complex maze of the medical and social service bureaucracies. Any program developed must be adaptable to the client and his/her specific problem or problems. Services would be established on a contractual basis.

A basic model that could be used for such a system is the AIDS Community Care Alternatives Program. This program is administered by Medicaid but is able to serve just 800 patients who meet the financial, social and clinical diagnosis of AIDS. This is not enough.

At present, individuals and families often have several case managers. This is costly and defeats the purpose of case management. Needed is a flexible system of case management capable of providing services to all members of the patient's family. This family case management system should be developed in community-based facilities, many of which are not currently HIV/AIDS provider sites.

RECOMMENDATION:

- *A community-based case management system for all persons with HIV/AIDS should be developed on a county-by-county basis.*

- *Reimbursement for this system should be shared by the State and the counties.*

IMPLEMENTATION STRATEGY:

- *The state should link currently existing services with new programs as they develop. The system must be flexible and adaptable to the needs of the patient and must provide standard levels of service delivery and include a contractual method to ensure compliance with established standards.*

- *The system should be phased in on a gradual basis starting with the highest incidence counties.*

- *The county-by-county case-management system should evolve into a coordinated program incorporating the AIDS Community Care Alternatives Program (ACCAP).*

ISSUE: ***ADOLESCENTS***

BACKGROUND/DISCUSSION:

The adolescent population is an especially difficult group to reach. At this age young men and women are awakening to the physical desires of their bodies and encountering the peer pressure of their friends. This is a challenging and critical time for adults to provide information to them about drugs and sex. If this is not done by their parents, institutions must assume the responsibility of informing these young people of the specific behaviors needed to avoid HIV infection. We need better programs to reach adolescents.

The extent of HIV infection in adolescents is not presently known, and can only be estimated based on the number of HIV/AIDS cases among individuals in their early twenties. There is a need to investigate HIV prevalence in adolescents and develop HIV/AIDS services specific to them, with special attention paid to adolescent females and homosexual males, the two adolescent groups most at risk.

Given the specific problems encountered in delivering services to this age group, the concept of "emancipation," which presently exists for treatment of sexually transmitted diseases, might be useful for treatment of HIV/AIDS.

RECOMMENDATION:

- *Programs should be developed to reach adolescents, as a specific HIV/AIDS population with distinct needs.*

IMPLEMENTATION STRATEGY:

- *The state should investigate the extent to which services specific to HIV/AIDS-infected adolescents are needed.*
- *The state should encourage and fund programs which provide education and services to high-risk, female and/or homosexual adolescents, with particular emphasis on the distinctive character of these populations.*
- *The state should look into the concept of "emancipation" in regard to HIV/AIDS testing and treatment of adolescents.*

ISSUE: ***STREET CHILDREN AND RUNAWAYS***

BACKGROUND/DISCUSSION:

Street children and runaways pose a particular problem for social service agencies. The first instinct of these children is to avoid contact with any agency that may return them to their former home or situation. Non-threatening and non-intrusive services work best with these young people. It is not surprising that the institutions, facilities or agencies providing the best services for street children are those that have been established with an specific emphasis on the young. Services and facilities needed include: "walk-in" centers offering food, shelter and clothing; small, non-intimidating health care clinics located in areas where these young people congregate; emergency shelters; and residential care facilities for young people with HIV/AIDS.

On the streets the need to survive often leads to sex for money or the use of drugs. Services should particularly target adolescent substance abusers, young people with HIV/AIDS and other sexually transmitted diseases, and pregnant teens.

Since peer pressure is a major force in modifying adolescent behavior, a peer-education and behavior-modification program would be effective with this population.

RECOMMENDATION:

- *Services should be expanded and/or developed and facilities pursued for street children and runaways.*

IMPLEMENTATION STRATEGY:

- *Services should particularly target substance abusers, young people with HIV/AIDS and sexually transmitted diseases, as well as pregnant teens.*
- *Facilities should include: "walk-in" centers offering food, shelter and clothing; small, non-intimidating health care clinics including HIV counseling and testing located in areas where these young people congregate; emergency shelters; and residential care facilities for young people with HIV/AIDS.*
- *A peer education program assisting in behavior modification should be developed for this population.*

ISSUE: *VOLUNTEERS*

BACKGROUND/DISCUSSION:

Voluntarism is one of the backbones of American society. Individuals volunteer for many reasons, but the feeling of gratification derived from helping is probably the most important. Services that would benefit from volunteers would include homemaking, hospice care, members of support groups and buddies, etc. However, volunteers--like everyone else--are afraid of AIDS. They must receive the necessary HIV/AIDS education to help reduce their anxiety. The use of tax credits for those performing volunteer services is one way of expanding the services to all groups in need.

At present the Department of Health as well as many public and private agencies throughout the state do not utilize resources from the business community to augment the pool of available volunteers. There is a need to examine the involvement of businesses in the volunteer effort.

RECOMMENDATION:

- *The number of volunteers providing HIV/AIDS services should be increased statewide.*

IMPLEMENTATION STRATEGY:

- *The state should increase education efforts to reduce volunteers' fear of HIV/AIDS patients.*
- *Tax credits or other creative tax incentives should be adopted by the state to attract volunteers to work with underserved populations.*
- *The state should call upon other public agencies and the business community to provide volunteers.*

ISSUE: ***DEVELOPMENTALLY DISABLED***

BACKGROUND/DISCUSSION:

The developmentally disabled with HIV/AIDS have thus far been almost completely overlooked. The actual prevalence of HIV/AIDS in the developmentally disabled population is not known and must be established through voluntary HIV testing policies in all facilities housing the developmentally disabled.

Developmentally disabled persons should enjoy the same rights to confidentiality, as well as pre- and post-test counseling and test as the everyone else.

Developmentally disabled persons and their families also need HIV/AIDS education by individuals familiar with this population. The curriculum for this education program could be developed as a joint venture between the Department of Health and the Department of Human Services.

Treatment is a related concern for the developmentally disabled with HIV/AIDS. The question of transfer of guardianship and policies developed to deal with it needs to be examined.

RECOMMENDATION:

- *The prevalence of HIV/AIDS in the developmentally disabled population should be established.*

IMPLEMENTATION STRATEGY:

- *Voluntary testing policies should be developed in all facilities that house the developmentally disabled. This should be a joint effort by the Department of Health and the Department of Human Services.*
- *Developmentally disabled persons and their families should be educated about HIV/AIDS at the appropriate level by individuals familiar with the population.*
- *A mechanism for transfer of guardianship should be investigated for HIV/AIDS-infected persons in special situations.*

ISSUE: ***TRANSPORTATION***

BACKGROUND/DISCUSSION:

Transportation to care and treatment for HIV/AIDS patients in New Jersey is a service which is often overlooked. This is particularly a problem in the southern part of the state, where individuals must often travel long distances to and from treatment centers and physicians. The goal of any new program (or of the expansion of an existing one) should be the capacity to provide transportation to and from all organizations and facilities serving HIV/AIDS patients. In particular, adequate numbers of vans, invalid coaches, and other vehicles are needed for all existing and future HIV/AIDS organizations and facilities.

The certificate-of-need or grant-application procedures currently in place can help to ensure that this issue is addressed and that the availability of transportation to services in the applicant's geographic area is not overlooked. Current programs for the elderly and the medically needy can serve as a foundation for the expansion of services to HIV/AIDS patients, especially in southern New Jersey. The cost of transportation for people with HIV/AIDS should be covered by Medicaid, Medicare, and/or third-party payers.

RECOMMENDATION:

- *Transportation must be available to and from all organizations and facilities serving HIV/AIDS patients.*

IMPLEMENTATION STRATEGY:

- *An adequate quantity of vans, invalid coaches and other vehicles must be provided for all existing and future HIV/AIDS organizations and facilities.*
- *All certificate of need or grant applications must address the issue of availability of transportation to services in the applicant's geographic area.*
- *Current programs for the elderly and medically needy should be investigated as a foundation for expansion of services to HIV/AIDS patients.*
- *The cost of transportation for people with HIV/AIDS should be covered by Medicaid, Medicare, and/or third-party payers.*
- *The development of any new program or clinic should take into account the availability of public transport.*

ISSUE: ***THE TREATMENT ASSESSMENT PROGRAM (TAP)***

BACKGROUND/DISCUSSION:

The Treatment Assessment Program (TAP), was established in the fall of 1989. The original purpose of the program was to bring into treatment those persons who were HIV positive but asymptomatic, in order to delay for as long as possible the onset of such debilitating illnesses as Pneumocistis Carinii pneumonia through the use of prophylaxis. The program has expanded, however, to include service provision to those who are diagnosed with full-blown AIDS.

To slow the progression of HIV disease, the Public Health Service recommends periodic clinical monitoring of the administration of prophylactic medications, such as AZT and aerosolized pentamidine, for most HIV-infected individuals. Without such care, it is likely that most HIV- infected people will gradually progress to full-blown AIDS.

The State actively encourages at-risk individuals to be tested for HIV. If prophylactic care is not provided to these identified people, our hospitals can expect to be overwhelmed by the estimated 50,000 to 70,000 New Jerseyans infected with HIV.

Access to treatment will buy precious time as scientists continue to search for more effective therapies. However, failure to provide access will not only result in needless suffering, but also in higher treatment costs for more expensive inpatient care.

There are now five TAP centers in New Jersey, and the success of the program in attracting individuals with HIV/AIDS has been considerable. Indeed, demand has resulted in a waiting period of up to five months for entry into the program, which needs to be expanded. One way to achieve this would be to extend TAP to existing community-based ambulatory care centers and group practice physicians' offices.

The TAP centers are presently dependent upon state grants for operation. Current fiscal constraints in state government will severely limit the ability of the TAP sites to expand in response to increasing demand.

In order to secure the place of TAP services several steps need to be taken and payment mechanisms investigated. All TAP services for hospital based TAP centers could be covered by the DRG system of hospital payment. At present there is no method for guaranteed reimbursement for free-standing TAP sites. A mechanism is needed for expansion of TAP services to non-hospital-based sites. The Medicaid and/or Medicare systems, other third-party payers and other funding sources in all the above settings need to be utilized in order to create wide access to this program. Funds are also required to purchase the prophylactic drugs such as AZT and pentamidine which are used in early intervention therapy.

Although the Food and Drug Administration (FDA) has licensed drugs for use in the treatment of HIV infection, these medications are frequently beyond the reach of New Jersey citizens. Lower-income people and often even those with jobs and health insurance cannot afford or gain access to recent and promising treatments. Those with minimal funds often have to impoverish themselves to become Medicaid-eligible.

RECOMMENDATIONS:

- *The Treatment Assessment Program, which provides early intervention care and other support services to asymptomatic/symptomatic HIV-infected individuals, should be expanded.*

- *Legislation should be enacted to fund a system sufficient to treat the 50,000 to 70,000 HIV-infected individuals in the state in accordance with the "Protocol for Clinicians" developed by the Department of Health in conjunction with the Academy of Medicine of New Jersey.*

IMPLEMENTATION STRATEGY:

- *The New Jersey State Legislature should appropriate sufficient funds to the State Department of Health to implement the Treatment Assessment Program (TAP) for voluntary HIV monitoring, prophylaxis, and treatment.*

- *The Department of Health should integrate Treatment Assessment Program services and HIV-related medications into a formalized reimbursement system under the auspices of the Department of Health.*

- *An evaluative mechanism should be devised before expanding TAP.*

- *A mechanism should be developed for ongoing reimbursement of TAP costs, both in-hospital based ambulatory care centers and non-hospital based ambulatory care centers; for example, from the Medicaid and/or Medicare programs when eligible, other third-party payers, public sources and private funds, if available.*

- *The state should improve access to TAP by expanding the currently existing sites and by extending the TAP concept to existing community-based ambulatory care centers and group practice physicians' offices.*

- *Access to TAP services should take no longer than two (2) to Three (3) weeks.*

- *The Department of Health should assist in the development and adoption of appropriate legislation.*

ISSUE: ***NUTRITION***

BACKGROUND/DISCUSSION:

Perhaps the most neglected area in the care and treatment of HIV/AIDS is nutrition. Proper nutrition is often not stressed as an important component of health care for anyone, and particularly not for those with HIV/AIDS. Nutrition encompasses both food and nutritional supplements. It should be recognized that PWA's in New Jersey not only lack information about proper nutrition but in many cases simply lack adequate food. There needs to be greater coordination of food banks on a countywide basis to provide food to the hungry.

Good nutrition messages need to be targeted particularly to low-income families, pregnant women, young children (through their parents) and to all persons with HIV/AIDS as a means of maintaining their body strength and immune systems. People with HIV/AIDS need dietary supplements which are reimbursable by third-party payers.

Persons with HIV/AIDS would benefit from consultations with a registered dietician or nutritional support team, or other knowledgeable person or organizations. Nutrition needs to be stressed in all educational material for people with HIV/AIDS.

RECOMMENDATION:

- *Access to adequate food proper nutrition should be stressed as an important component of health care for everyone, and particularly for those with HIV/AIDS.*

IMPLEMENTATION STRATEGY:

- *Good nutrition messages should be targeted particularly to low-income families, pregnant women, young children (through their parents) and for all persons with HIV/AIDS.*
- *Dietary supplements, reimbursable by third-party payers, should be made available to the above groups and individuals.*
- *Nutrition should be stressed in all educational material for people with HIV/AIDS, and every HIV/AIDS patient should receive a consultation with a registered dietician, nutritional support team, or other knowledgeable persons or groups.*
- *Grant applications for the care and treatment of PWA's should include a nutritional component.*

ISSUE: ***HEALTH CARE PERSONNEL - GENERAL***

BACKGROUND/DISCUSSION:

There is a national shortage of health care personnel, and New Jersey shares in it. The state is caught between two major metropolitan areas, which aggravates the situation. The areas of New Jersey most affected by the shortage of health care personnel are those which traditionally have had problems recruiting qualified individuals: the inner-city and rural areas of the state. There is a need for programs encouraging health care personnel to work in inner cities and rural areas, both with HIV/AIDS patients and others.

One policy the state might explore is the establishment of a program which either provides tuition or buys out loans of health-care personnel who are willing to work in inner-city and rural areas and/or with HIV/AIDS patients. In particular, students in the health-care field need to be encouraged to become nurses' and physicians' assistants.

There is much concern in New Jersey about the lack of physicians currently treating HIV/AIDS populations, especially in inner-city and rural areas. The problem might be alleviated by assisting new medical school graduates in starting practices in these areas. Although these physicians may not remain permanently in these areas, services could be continued by new graduates.

Low Medicaid reimbursement rates to physicians providing ambulatory care--especially those in non-hospital-based clinics and in urban and rural areas--is one of the most serious factors affecting HIV/AIDS services there. In order to establish a viable program, a realistic method and rate of reimbursement is needed.

Nationally the problem of finding adequate numbers of nurses to fill available positions has reached crisis level. Nurses specializing in the care of persons with HIV/AIDS are in particularly short supply.

Additionally, the role of nurse practitioners is underutilized in the treatment of HIV/AIDS. Nurses acting in this expanded role enhance the flexibility of service-provision programs. Measures to aid further development of this valuable resource need to be investigated. The use of nurse practitioners for the treatment of HIV/AIDS patients should be a top priority state goal.

RECOMMENDATIONS:

- *Programs should be established to encourage health care personnel to work in inner-cities and rural areas and/or with HIV/AIDS patients.*
- *Physicians and dentists should be encouraged to treat in neglected, inner-city and rural areas and/or HIV/AIDS populations.*
- *Programs should be established to educate and expand the role of nurse practitioners, in regard to HIV/AIDS.*

IMPLEMENTATION STRATEGY:

- *The state should establish a program to either provide tuition or buy out loans of health care personnel who are willing to work in inner-city and rural areas and/or with HIV/AIDS patients.*
- *The state should require that all health care students have medical insurance.*
- *The state should mandate disability insurance for all health care students and non-salaried personnel, similar to the Yale Medical Student Insurance Plan.*
- *The state should assist new medical school graduates in establishing practices in inner-city and rural areas.*
- *The state should review Medicaid reimbursement rates to physicians who provide ambulatory care, especially those in non-hospital-based clinics and in urban rural areas.*
- *The state should pursue as a top priority the use of nurse practitioners for the treatment of HIV/AIDS patients.*

- *The state should require the ongoing HIV/AIDS education of all health care personnel as a requirement for facility and professional licensure or certification. (There is a minority opinion that, although health care professionals should receive necessary HIV/AIDS education, it should not be a requirement for licensing certification.)*

ISSUE: ***HEALTH CARE PERSONNEL - PHYSICIANS' ASSISTANTS***

BACKGROUND/DISCUSSION:

The medical care and treatment system for AIDS patients and HIV-infected individuals is currently overwhelmed at every level of intervention. There is a tremendous need for medical and other health care personnel to treat the growing numbers of people affected by this epidemic.

Physicians' assistants would greatly enhance service provision in clinics, hospitals, mental health centers, and substance abuse and prison health centers. Certain neglected geographic locations and populations might also benefit greatly from the use of physicians' assistants.

Throughout the United States, physicians' assistants are integral members of the treatment teams of hospitals, clinics and private practices. But not in New Jersey. This is especially egregious in that New Jersey has one of the best physicians' assistant training programs in the nation at the University of Medicine and Dentistry. This program is training physicians' assistants for service to their communities everywhere but in New Jersey.

New Jersey has a training program for the education of physician assistants, yet at the same time it is one of the few remaining states which does not allow for their licensing and practice. This is occurring at a time when physician assistants could be providing the medical care and treatment for HIV/AIDS patients that is so desperately needed.

In December 1990, the New Jersey Board of Medical Examiners voted to establish a pilot program for the use of physicians' assistants. This half-measure should be reconsidered and physicians' assistants should be made legal, certified, and licensed members of the New Jersey health care community as soon as possible.

RECOMMENDATION:

- *Physicians' Assistants should be employed as one of the most valuable components of the health care delivery system for especially certain neglected geographic locations and populations.*

- *Legislation should immediately be enacted which allows for the licensing and practice of physicians' assistants in New Jersey.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should assist in the development and adoption of appropriate legislation.*

- *The State Legislature and the Governor must immediately enact legislation to allow these valuable health practitioners to practice in the State of New Jersey.*

- *The state should require the ongoing HIV/AIDS education of all physicians' assistants as a requirement for facility and professional licensure or certification. (There is a minority opinion that, although all health care professionals should receive necessary HIV/AIDS education, it should not be a requirement for licensing certification.)*

ISSUE: ***AIDS DRUG DISTRIBUTION PROGRAM (ADDP)***

BACKGROUND/DISCUSSION:

One of the major goals of effective treatment of any chronic disease is to maintain an individual as productive, independent, and free from the consequences of disease for as long as possible. When illnesses occur, effective, accessible, affordable treatment must be provided to return the individual to maximum normal functioning. Early intervention in the treatment of HIV-infected persons requires accurate diagnosis, an acceptable treatment plan, and treatments that are accessible and affordable to prevent further disease and to return ill individuals to health. The necessary medications to provide this care are expensive and must be taken on a long-term basis.

ADDP provides medications specifically for the treatment of HIV or its frequently associated illnesses on an outpatient basis. It has allowed individuals and families with working members to have their infected members treated with necessary medications (AZT, Alpha-Interferon, pentamadine) without becoming destitute or leaving the work force prematurely. This program has also prevented other illnesses which may have required more expensive and extensive hospital treatment.

ADDP has been inexpensive for the state to administer and the paperwork is minimal for the patients. It continues to provide for HIV-infected persons who have been affected by their infection and who are able through appropriate treatment to continue their normal activities.

RECOMMENDATION:

- *The AIDS Drug Distribution Program should be continued and expanded.*

IMPLEMENTATION STRATEGY:

- *The state will continue to apply for and use federal dollars for this program.*
- *State monies will be assigned to fill the necessary budget for full implementation and continuance of this program.*
- *New drugs will have rapid evaluation for inclusion in this program; e.g., DDI.*
- *Other drugs that are frequently used in outpatient treatment of HIV- infected individuals will be considered for inclusion; e.g., Acyclovir, Ketoconazole, Bactrim.*

NON-TRADITIONAL MEDICINE:

In developing a plan for the treatment HIV/AIDS the tendency is to relate new recommendations to traditional medical practice, but there are alternatives to these practices which at least offer solace and sometimes therapeutic benefit to the patient. The prevention of heart disease which is mainstream medical treatment now was not at one time. Through lowering of cholesterol and other dietary practices is a good example. Acupuncture is another; although still not a "mainstream" medical technique, it at least is no longer regarded with xenophobic condescension. At present. the Lincoln Medical Center in the Bronx, New York, has endorsed its effectiveness in the treatment of substance abuse.

RECOMMENDATION:

- *The state must evaluate non-traditional medical treatment for treatment of HIV/AIDS.*

IMPLEMENTATION STRATEGY:

- *The state should develop reimbursement mechanism for non-traditional medical practice once there efficacy has been demonstrated.*

LEGISLATION AND REGULATION

ISSUE: ***HIV PREVENTION/EDUCATION: UNIVERSAL PRECAUTIONS***

BACKGROUND/DISCUSSION:

Although the potential for hepatitis B virus (HBV) transmission in the workplace setting is greater than for HIV, the modes of transmission for these two viruses are similar. Both have been transmitted in occupational settings only by percutaneous inoculation or contact with an open wound, nonintact skin, or mucous membranes to blood, blood-contaminated body fluids, or concentrated virus. Blood is the single most important source of HIV and HBV in the workplace setting.

Protection measures against HIV and HBV for workers should focus primarily on preventing these types of exposures to blood through the use of universal precautions.

The standardized use of universal precaution measures will also serve to prevent discrimination towards HIV-infected patients. They will not be singled out and feared because health care professionals will be consistently taking appropriate transmission protection steps with all patients.

RECOMMENDATION:

- *Legislation and regulation should be adopted requiring the employment of universal precautions in all licensed health care facilities and clinical laboratories, first aid, rescue and ambulance squads, law enforcemen agencies, correctional facilities, fire departments and funeral homes.*

IMPLEMENTATION STRATEGY:

- *The Commissioner of Health should prepare and distribute recommended regulations for the adoption of universal precautions.*
- *The immediate formulation and implementation of such regulations is essential.*
- *The Department of Health should urge the Centers for Disease Control to update definitions and guidelines to include state-of-the-art practices.*

ISSUE: ***CONFIDENTIALITY OF HIV-RELATED INFORMATION***

BACKGROUND/DISCUSSION:

HIV/AIDS is unlike any other disease of modern times because it is incurable and highly stigmatized and because of the groups infected at the start of the epidemic - homosexuals and intravenous drug abusers. Information inadvertently released regarding a person's HIV status has resulted in loss of employment, loss of health insurance, eviction from housing, and ostracism by family and friends. Recorded patient information, for adults as well as children, needs to be kept in strictest confidence; any breach of confidence may represent risk to insurability, job security, and other civil liberties.

In order to prevent these disastrous repercussions from occurring, the information concerning an individual's HIV status must be thoroughly protected by law. Careful attention needs to be paid to maintaining confidentiality and to protecting records from any unauthorized disclosure. The ability of health agencies to assure confidentiality, and the public's confidence in that ability, are crucial to efforts to increase the number of persons requesting counseling and medical intervention.

RECOMMENDATIONS:

- *The enforcement of the state HIV/AIDS confidentiality legislation should be strengthened.*

- *The standard of confidentiality for HIV and AIDS information that is contained in this legislation should apply to all medical records and medical information at this time.*

IMPLEMENTATION STRATEGY:

- *Public Law 1989, Chapter 303 should be amended to authorize misdemeanor charges for violations, and to authorize substantial civil penalties enforceable by the appropriate state agency for breaches in confidentiality.*

- *The Department of Health should plan and coordinate language for the amendment of the statute through the Department's Office of Legal and Legislative Affairs.*

ISSUE: *HIV TESTING AND REPORTING*

BACKGROUND/DISCUSSION:

Patient assessment and tracking (surveillance) are fundamental to the control and prevention of disease. In an effort to limit the continuing spread of HIV infection, and thereby minimize AIDS, the Department of Health has implemented an assessment system.

The appropriate release of information - particularly personal identifying information - needs to be safeguarded when implementing HIV and AIDS-related surveillance systems. These provisions are necessary to preserve the integrity and usefulness of public health efforts.

Historically, the public health approach has utilized named reporting of disease in order to identify and treat infected persons, as well as their contacts. Opposition to named HIV reporting centers on the facts that treatment has not until recently been available for infected persons, and the concern that the unauthorized release of information due to breaches in confidentiality has led to severe discrimination and ostracism.

HIV reporting has been approached in a variety of ways by the different states. Nine states have confidential reporting with names and identifiers; 16 states have mixed reporting with names and identifiers but also allow the option of anonymous testing; four states have anonymous reporting, but with names reported in special situations; fourteen states have reporting with demographic information but without names; and eight states have no reporting requirements for HIV infection.

RECOMMENDATIONS:

- *Legislation or regulation should be introduced to ensure that clients receive information regarding both confidential and anonymous HIV testing; that patients understand the possible consequences of a positive HIV diagnosis, and that clients have easy access to anonymous testing, if they should choose such a course. (This recommendation is required until other appropriate legislation is enacted addressing HIV/AIDS confidentiality, discrimination, and bias-related violence.)*

- *Legislation should immediately be enacted to repeal the requirement of "identified" reporting of HIV infection.*

IMPLEMENTATION STRATEGY:

- *Legislation should be enacted or regulation promulgated to require that the difference between confidential and anonymous testing is explained to all clients in the counseling discussions prior to any HIV testing, and that informed consent be obtained prior to confidential HIV testing. Un-professional conduct regarding compliance with this requirement will be appropriately addressed by the Department of Health through the removal of grant funds, and through licensure and certification monitoring.*

- *The Department of Health should encourage and assist in the development and adoption of appropriate legislation or regulation.*

- *The State Department of Health should prepare regulations for providing anonymous HIV testing at all state-sponsored testing sites.*

ISSUE: ***HIV PREVENTION: PRENATAL CARE***

BACKGROUND/DISCUSSION:

The Department of Health's second statewide HIV Maternal/Neonatal serosurvey was completed in New Jersey in the fall of 1989. This blinded survey represented a 100% sampling of all the newborns for a three-month period. The results indicate a statewide prevalence of 0.52 percent, or approximately 600 HIV-positive births per year. This prevalence reflects very closely the serosurvey which was conducted in 1988 which yielded a statewide prevalence of 0.49 percent.

HIV-positive births have occurred in virtually every New Jersey county over the two year period which has been studied. The dramatically increasing number of cases of women and children indicate that the implications of this data warrant immediate attention by all practitioners.

RECOMMENDATIONS:

- *The Department of Health should promulgate regulation that requires that prenatal care programs, physicians, and community clinics provide pregnant women with counseling on HIV infection, including the risks for HIV infection, the issues related to antibody testing, the availability of anonymous testing elsewhere, and the existing options regarding the availability of early medical care for women and infants.*

- *The Department of Health should encourage substance abuse treatment for pregnant women.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should assist in the development and adoption of appropriate regulation.*

- *The Department of Health should plan, coordinate, and consult with perinatal centers and Treatment Assessment Programs to develop and implement protocols for the management of pregnant women with manifestations of HIV infection.*

ISSUE: ***CREATION OF A COMMISSION ON AIDS***

BACKGROUND/DISCUSSION:

The creation of three advisory committees by the Commissioner of Health has been instrumental for the development of recommendations for inclusion into a state HIV/AIDS Plan. It is the conclusion of the Subcommittee that many issues have only been initially or

preliminarily explored due to the time constraints for submission of the plan to the Governor.

RECOMMENDATION:

- *An independent Commission on AIDS, comprised of representatives of state agencies with current or potential involvement in the HIV/AIDS epidemic, AIDS community-based organizations, community and business leaders, AIDS health care practitioners, civil rights leaders, and representatives of communities most severely affected by the epidemic (people of color, gay men, lesbians, recovering intravenous drug users, AIDS activists and advocates, and persons with AIDS), as well as equitable geographic representation, should be established by legislation or Executive Order to advise on, formulate, coordinate, and implement statewide HIV/AIDS-related policies. Dedicated funding should be attached to the establishment of this Commission on AIDS in order to pay for the transportation and other meeting-related expenses of the members, particularly those with HIV and AIDS.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should assist in the immediate development of the Commission on AIDS.*

ISSUE: ***CARE AND TREATMENT: HEALTH CARE PROXIES AND LIVING WILLS***

BACKGROUND/DISCUSSION:

The symptomalogy of AIDS, which can take its toll in affecting various body systems including brain functioning, can severely limit mental capacity and decision-making capabilities - rendering a person periodically incompetent. Due to the fact that these periods of compromised decision-making may be brief and reversible, it would serve patients well to be able to appoint a health care proxy to permit substitute medical decision-making during periods of incompetence. This arrangement would maintain a patient's autonomy over their medical decisions and care when they are able, and would ensure confidence that decisions and arrangements regarding medical care and treatment are appropriately carried out during periods of incompetence.

AIDS is often characterized by a slow progression of symptoms and diseases which repeatedly bombard an individual due to an extremely compromised immune system. Although there have been many medical advances in the treatment of the diseases which take hold in a symptomatic patient, the result eventually is death. There has been ongoing interest and exploration to enable terminal patients to take as much control over their medical care and decision-making as possible, particularly regarding the use of exceptional means for saving life. Self-directing living wills would enable patients to describe, in advance of the need, their preferences regarding the provision of extraordinary medical care to prolong or save life.

RECOMMENDATION:

- *Legislation should be enacted which authorizes the appointment of health care proxies to permit substitute medical decision-making during periods of incompetence, and authorizes self-directing living wills setting forth an individual's preferences regarding the provision of extraordinary medical care to prolong life.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should assist in the development and adoption of appropriate legislation.*

ISSUE: ***INSURANCE COVERAGE FOR INDIVIDUALS WITH SEVERE DISABILITIES, INCLUDING AIDS AND ADVANCED HIV DISEASE***

BACKGROUND/DISCUSSION:

Under the Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA), workers who leave their employment as a result of disability may continue their group insurance coverage on an individual basis for up to 29 months. These continuation plans may be purchased for 102% of the group rate for the first 18 months, and for 150% of the group rate between 18 and 29 months. After 29 months, most disabled people will qualify for Medicare. Although continuation plans are generally less costly than individual policies, they are often too expensive for unemployed people with disabilities. Additionally, because of their disability, these people are generally denied access to individual health coverage.

Many people with chronic diseases or medical conditions, including people with AIDS and HIV infection, are deemed uninsurable by private carriers. Many HIV-infected people are not sufficiently disabled to obtain Medicaid, yet cannot obtain individual health plans in the private sector.

High-risk plans can be useful to uninsurable people only if they are sufficiently comprehensive and reimburse a broad range of medical and ancillary services. Such policies should also be reasonably affordable; although generally high-priced premiums for comparable policies in the private sector may serve as guides. Furthermore, high-risk pools are developed primarily to assist people with chronic conditions in meeting their health care needs. Unfortunately, most health policies contain pre-existing-condition clauses which deny coverage for a predetermined time period for illnesses diagnosed or treated preceding the effective date of the plan. While such provisions may decrease claims-related costs, they defeat the purpose of the policy supporting the creation of high-risk pools -- to guarantee coverage for individuals denied insurance in the private sector because of their pre-existing conditions.

Note: This issue will need to be further addressed as issues regarding the State's Uncompensated Care Trust Fund are explored.

RECOMMENDATION:

- *Legislation should be enacted to ensure insurance coverage for individuals with severe disabilities, including those with AIDS or advanced HIV disease.*

IMPLEMENTATION STRATEGY:

- *The Legislature should authorize payment of Medicaid funds to cover individual private health insurance premiums for people with severe disabilities, including AIDS and advanced HIV disease.*

- *The Legislature should authorize the Department of Insurance to create a high-risk pool to provide reasonably affordable and comprehensive health insurance for individuals who cannot obtain such coverage from private insurers due to pre-existing medical or disabling conditions. Funding for the pool should come from private health insurers doing business in the state, state sources, and reasonably-priced individual premiums.*

- *The State Legislature should require private health insurers doing business in the state to offer reasonably affordable and comprehensive group health plans to private, not-for-profit organizations providing services to people with AIDS and HIV infection.*

- *The State Legislature should prohibit the use of HIV antibody tests, or other future markers of HIV infection, for health insurance underwriting.*

- *Planning and coordination is required for implementation by the State Departments of Insurance, Health, and Human Services, and by the State Legislature. These recommendations work within the current financing system, but maintain that both the private and the public sector share responsibility to ensure adequate health care for people with HIV disease.*

- *The Department of Health should assist in the development and adoption of appropriate legislation.*

ISSUE: ***HIV PREVENTION IN THE WORKPLACE***

BACKGROUND/DISCUSSION:

The workplace is a critically important setting in which to achieve the goals of fair treatment and education. Most adult Americans are employed; work is not only a source of financial support but also a vital link to a community of coworkers. Former United States Surgeon General C. Everett Koop declared: "Worksites in particular can serve as effective settings in which to provide AIDS education. And the ideal time to educate your employees about AIDS is before your corporation has its first AIDS case." He called on American businesses to "set the example for being fair and objective and for not succumbing to groundless hysteria."

Any employee who is diagnosed with a catastrophic illness faces potentially devastating consequences. While the threats of death or prolonged suffering are paramount, just as damaging are concerns about one's ability to live with the illness--to continue working, to receive health benefits, and to experience the emotional support and assistance of friends and colleagues. Employment is more than a means to earn a living; it defines an essential part of the lives of most people. Working can make an important contribution to the physical and mental well-being of people dealing with serious illness. With the proper support, these employees can continue to make an important contribution to their employers.

When the catastrophic illness is a stigmatized one--as cancer used to be and AIDS is today--the employee faces even greater obstacles. The stigma surrounding AIDS is harmful to the interests of the affected individuals, to employers, and ultimately to society. There is no relevant difference between the way employers should treat employees with lung cancer or kidney disease and the way they should treat people with AIDS or HIV infection.

Each company or agency must examine its existing policies and settings to determine the appropriate response to HIV infection and AIDS in the workplace. In some instances existing policies concerning disabling illness may be adequate to cover AIDS; in others, a review of such policies may reveal gaps that affect people with all such illnesses and disabilities. In all cases, however, education about AIDS is a new and pressing need, both to maintain a stable work environment and to give employees information about personal risk reduction.

Economic imperatives, as well as social responsibility, make it essential for American business to address AIDS. Just as the workplace can become a model for responding to AIDS, that response can become a model for addressing all forms of catastrophic illness.

RECOMMENDATION:

- *Legislation incorporating the "Ten Principles for the Workplace," as developed by the Citizens Commission on AIDS for New York City and Northern New Jersey, should be enacted to guide workplace response to this fatal disease. These principles are intended as a framework for all employees, unions, and other employee representatives and business organizations that share the responsibility of responding to AIDS:*

1. *People with AIDS or HIV (Human Immunodeficiency Virus) infection are entitled to the same rights and opportunities as people with other serious or life-threatening illnesses.*

2. *Employment policies must, at a minimum, comply with federal, state, and local laws and regulations.*

3. *Employment policies should be based on the scientific and epidemiological evidence that people with AIDS or HIV infection do not pose a risk of transmission of the virus to coworkers through ordinary workplace contact.*

4. *The highest levels of management and union leadership should unequivocally endorse nondiscriminatory employment policies and educational programs about AIDS.*

5. *Employers and unions should communicate their support of these policies to workers in simple, clear, and unambiguous terms.*

6. *Employers should provide employees with sensitive, accurate, and up-to-date education about risk reduction in their personal lives.*

7. *Employers have a duty to protect the confidentiality of employees' medical information.*

8. *To prevent work disruption and rejection by coworkers of an employee with AIDS or HIV infection, employers and unions should undertake education for all employees before such an incident occurs and as needed thereafter.*

9. *Employers should not require HIV screening as part of general pre-employment or workplace physical examinations.*

10. *In those special occupational settings where there may be a potential risk of exposure to HIV (for example, in health care, where workers may be exposed to blood or blood products), employers should provide specific, ongoing education and training, as well as the necessary equipment, to reinforce appropriate infection control procedures and ensure that they are implemented.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should immediately work with the State Legislature towards the passage of appropriate legislation.*

ISSUE: ***HIV PREVENTION, CARE AND TREATMENT: CIVIL RIGHTS - LAW AGAINST DISCRIMINATION (LAD)***

BACKGROUND/DISCUSSION:

Many health care professionals have responded admirably, often courageously, in treating people with HIV disease. However, since the beginning of the HIV/AIDS epidemic, some providers have evaded their ethical responsibilities by refusing to care for these people. In spite of advisory opinions by the American Medical Association, the American Nurses Association, the federal Centers for Disease Control, former United States Surgeon General C. Everett Koop, and the State Board of Medical Examiners, discrimination by health care providers has not abated.

Although the State Division on Civil Rights accepts discrimination cases involving private health care practitioners, and health-related complaints received by the State Public Advocate have been increasing, it remains unclear if the LAD applies in these situations.

RECOMMENDATION:

- *Legislation should be adopted to ensure that people with HIV/AIDS are not subject to discrimination.*

IMPLEMENTATION STRATEGY:

- *The Legislature should amend the definition of "A place of public accommodation" to include "offices of health care practitioners" and "nursing homes."*
- *The Legislature should amend LAD to include "sexual orientation" as a protected classification*
- *The Attorney General's Office should release the Advisory Opinion clarifying the application of the LAD to people with AIDS and HIV infection.*
- *The Legislature should strengthen and adequately fund enforcement efforts by the State Division on Civil Rights.*
- *The Legislature should plan and confront this challenge in coordination with the Department of Health and the Office of the Attorney General.*
- *The Department of Health should assist in the development and adoption of appropriate legislation.*

THE HIV/AIDS COMMUNITY ADVISORY COMMITTEE MEMBERS

Jane Adams, R.N.
President
New Jersey State Nurses Association
Trenton

Marilyn Aguirre-Molina
Assistant Professor
Department of Environmental and Community Medicine
UMDNJ - RWJ Medical School
Piscataway

Senator Gabriel M. Ambrosio
District 36
Lyndhurst

Paul Armstrong
Chairman
New Jersey Bioethics Commission
Bridgewater

Marion Banzhuf
Coordinator
New Jersey Women and AIDS Network
New Brunswick

Mary G. Boland, R.N., M.S.N.
Director
Children's Hospital AIDS Program
Newark

John Brooks
Executive Director
Institute for Human Development
Atlantic City

Assemblywoman Stephanie Bush
District 27
East Orange

Kenneth Chance, D.D.S.
Assistant Dean for External Affairs and Urban Resource Development
UMDNJ - New Jersey Dental School
Newark

Douglas Costabile, M.D.
President
Medical Society of New Jersey
Lawrenceville

John B. Dalton
Senior Regional Manager
State Government Affairs
Hoffmann LaRoche, Inc.
Nutley

Ronnie Davidson
Associate Director for Continuing Medical Education
Lawrenceville

Sonia Delgado
The New Jersey Senate
Trenton

Dorothy Fleming
Executive Director
New Jersey State Nurses Association
Trenton

Barbara Ford
AIDS Coordinator
Dept. of Health & Human Services
Newark

Cathy Forrester, M.D.
Atlantic City Medical Center
Atlantic City

Lawrence D. Frenkel, M.D.
Chairman
UMDNJ-Robert Wood Johnson Medical School
New Brunswick

Kelly Ganges
New Jersey General Assembly
State House Annex
Trenton

THE HIV/AIDS COMMUNITY ADVISORY COMMITTEE MEMBERS

Debby R. Hoffman
Executive Director
New Jersey Primary Care Association
at the Center for Health Affairs
Princeton

Riki Jacobs
New Jersey Association on Correction
Trenton

Gladys Jimenez, R.N.
AIDS Outreach Specialist
Raritan Bay Medical Center
Perth Amboy

Carol J. Kientz, R.N., M.S.
President
Home Health Assembly of NJ, Inc.
Princeton

Jeffrey Lampl
Executive Director
Hyacinth Foundation
New Brunswick

Dennis Quinlan, M.D.
Chief, Section of General Medicine
UMDNJ - New Jersey Medical School
Newark

Donald Ransom
Newark

Herbert Roeschke
President
New Jersey Health Officers Association
Toms River

Joan Scerbo
c/o Senator Gabriel M. Ambrosio
Lyndhurst

Carl Sigmon
Plainfield

Irene Jesse-Hunt
Coordinator
Mayor's AIDS Task Force
Division of Health
Jersey City

Peter Jewell
Somerville

Rosemarie A. Johnson
Belleville

Patricia Kloser, M.D.
Director
Women's Clinic
UMDNJ - University Hospital
Newark

Senator Wynona M. Lipman
District 29
Newark

Bernard Rabinowitz
New Jersey Focus
Nutley

Christine Reyelt, M.D.
Citizens Commission on AIDS
St. Joseph's Hospital and Medical
Center
Paterson

Ronald Rouse
Medical Society of New Jersey
Lawrenceville

Louis P. Scibetta, F.A.C.H.E.
President
New Jersey Hospital Association
Princeton

Karen Sofield
Bloomfield

THE HIV/AIDS COMMUNITY ADVISORY COMMITTEE MEMBERS

Diana Stager
Director of Planning
New Jersey Hospital Association
Princeton

Camilla Vance
Morristown

Alan Weiss
Linden

Theresa Hauber
The Citizen's Committee on Biomedical Ethics
Summit

Mary S. Strong
Chairman
The Citizen's Committee on Biomedical Ethics
Summit

Debra Walker
Belleville

Guy Weston
Voorhees

APPENDIX II

THE DEPARTMENTS OF THE STATE OF NEW JERSEY HIV/AIDS ADVISORY COMMITTEE'S RECOMMENDATIONS TO THE COMMISSIONER OF HEALTH JANUARY 1991

The Departments of the State of New Jersey HIV/AIDS Advisory Committee included representation from the following state departments: Community Affairs, Corrections, Education, the Governor's Office, Health, Higher Education, Human Services, Insurance, Labor, Law and Public Safety (Office of the Attorney General), Personnel and the Public Advocate.

During the meetings of this group, the departments provided and discussed information on the following topics: each department's existing HIV/AIDS-related programs; the extent of any mandated programs; the impact of any federal requirements; program priorities; external and internal influences; interagency cooperation; methods of program evaluation and programs which should be implemented. Most of the departments address HIV/AIDS issues as part of their normal operations, and have no specific HIV-related budget or staff. A few of the departments, such as Health and Education, have dedicated staff, budgets, and grants specifically to address HIV/AIDS.

There were a number of interagency cooperative efforts on HIV/AIDS issues already in place. For example, the Departments of Higher Education and Health have a Letter of Agreement; the Departments of Health and Human Services have Letters of Agreement and are sharing data; the Departments of Education and Health are cooperating on several initiatives; the Departments of Corrections and Health routinely confer on HIV issues.

In some state departments, such as Corrections, Education and Higher Education, "local rule" impacts upon the ability of the department to implement its guidelines and policies. Local rule extends to local school boards, individual college administrations, and county and municipal jails. The Committee agreed that many of the issues and problems brought up in discussions of HIV/AIDS were inherent in the health care system. The HIV epidemic has served to dramatically focus attention on them.

Several recurring themes emerged during the committee discussions, and are reflected in the recommendations. One theme was that HIV-infected persons should be "mainstreamed," not treated or housed in separate facilities. Many of the services required by this population are also required by other populations. Within some issues, such as housing and children's services, implementation of policies and/or services for HIV/AIDS-infected persons could be done as a pilot project. The results could be evaluated and if the policies or services were appropriate, could be applied to other populations that need the same services.

Another overall theme was centralization of services across state departments. As with the health care system in general, information about services, policies and authority over services tends to be scattered throughout individual departments and divisions.

A third theme was coordination of services, programs, policies, and information across state departments. This theme also occurs in the general health care system.

The following recommendations are organized by issue, with a brief overview of the existing situation, and the intent(s) of the recommendations. The issues include residential health care/housing; pediatric, adolescent and family services; substance abuse treatment; special populations; prevention, education and testing; finance; coordination of services; and human rights. Some issues, such as coordination of services, finance and human rights are included under a specific issue, as well as in their own broad category.

In preparing these recommendations, the committee also made the following assumptions:

- *The wheel should not be reinvented. When an existing program is doing the job alone, or can be modified, expanded, or combined with another existing program to do the job, no new program should be created.*

- *Whenever possible, community-based solutions to service delivery problems should be utilized.*

- *Because there may be little or no "new" money available for proposed programs, care should be taken that they should be cost-effective. There is no point in proposing the creation of programs that cannot be paid for.*

- *There should be reasonable means to finance, or reimburse for, proposed new programs, even if this means some cost shifting and reallocation.*

- *Computerized communication systems should be available to link proposed programs and services, in order to maximize the benefits of case management.*

- *Whenever possible, programs and services should respect the integrity of the family. For the purposes of this plan, "family" is defined as those individuals whose presence is significant to the client, irrespective of biological ties or legal relationships.*

- *Care will be taken to minimize bureaucratic red tape in connection with any proposed programs and services. Living with HIV/AIDS is already difficult enough.*

- *HIV/AIDS serves only to reinforce the realization that our present health care system is seriously deficient.*

- *Evaluation and accountability mechanisms should be a component of any state plan for HIV/AIDS.*

RESIDENTIAL HEALTH CARE/HOUSING

Persons infected with HIV have an acute need for housing at all levels, but particularly for intermediate levels of care such as nursing homes, residential health care facilities, transitional housing, boarding homes and congregate care facilities. Currently, due in part to financing issues and discrimination, there is a lack of such facilities in New Jersey. The services that are provided tend to be fragmented. Because of the lack of coordinated services, HIV-infected persons may be kept in an inappropriate setting, such as an acute care hospital, or one of the few highly reimbursed nursing homes that accepts AIDS patients. The level of care in either type of facility is expensive, and clinically and socially inappropriate. The issues that must be discussed and resolved before appropriate housing services can be provided include financing and reimbursement, coordination of the various executive agencies that oversee housing, and removal of the barriers of discrimination.

The recommendations are designed to assess the current situation, examine coordination of services, and address financing/reimbursement and human rights issues.

Assessment

RECOMMENDATION:

- *The state should obtain information to assess the need for housing for HIV-infected persons.*

IMPLEMENTATION STRATEGY:

The state should:

- *initiate a review and a needs assesment of existing residential care facilities, particularly in regard to accessibility and funding of such facilities, in or near affected communities. This review would include an examination of the need for emergency housing for HIV positives not eligible for current programs, and the need for supported housing.*

- *review previous studies and other available material on improving housing and residential care. These materials suggest that substantial improvements in the provision of services are possible without an expenditure of large amounts of new revenue.*

Coordination

RECOMMENDATION:

- *The state should take steps to coordinate information and services on housing at the state level.*

IMPLEMENTATION STRATEGY:

The state should:

- *centralize the information available within state departments on housing, licensing, regulations and Certificates of Need, so that persons requesting information need make only one visit, instead of multiple visits to different departments.*

- *concentrate in one place the responsibility for licensing and overseeing services for Persons with AIDS (PWAs) in residential facilities. The final authority to approve new HIV-related services and ongoing inspection should be located in one agency with a cooperative relationship with the other traditionally responsible agencies.*

- *encourage the Department of Community Affairs' Bureau of Housing Services to continue the dialogue recently initiated with the Departments of Health and Human Services on comprehensive planning for the homeless. The Department should continue to explore the availability of resources, such as federal McKinney funding, for housing initiatives.*

- *implement a mechanism to encourage innovative solutions to housing problems under the licensing standards of the Department of Community Affairs, Department of Human Services and the Department of Health; these variations should be monitored for effectiveness. This mechanism could then be expanded to other populations with residential care needs.*

- *convene an on-going Interdepartmental Housing Initiatives Task Force to explore housing programs, funding sources and opportunities that will address the diverse housing needs of the HIV/AIDS population, including the use of Homelessness prevention, Transitional Housing, Life Safety Improvement Program and Emergency Housing Program funds.*

- *encourage the Departments of Health and Corrections to work together to locate nursing homes and/or drug treatment facilities for the care and treatment of inmates, either on an interim or long-term care basis.*

Financing/reimbursement

RECOMMENDATION:

- *The state should work toward the provision of housing for HIV-infected persons through appropriate funding or other financial initiatives.*

IMPLEMENTATION STRATEGY:

The state should:

- *critically examine the discontinuities in funding of residential services for PWAs; look at permitting state funding for appropriate shelters and for maintaining HIV-positive persons at the appropriate level of care (e.g. increase the state portion of the SSI grant).*

- *examine the feasibility of augmenting reimbursement by using the Medicaid personal care service option to pay for some of the enhanced services required by this population. Use of this option could bring more federal dollars into the system for Medicaid eligibles.*

Human Rights

RECOMMENDATION:

- *The state should ensure that access to appropriate housing for persons infected with HIV is not barred because of human rights violations.*

IMPLEMENTATION STRATEGY:

The state should:

- *pursue greater access to existing facilities for HIV-positive persons by enforcing the antidiscrimination requirements of state and federal law; in the meantime, existing services, such as nursing home care, should be fully and appropriately utilized.*

- *initiate dialogue with nursing homes, and appropriate associations, on the existing regulations that prohibit refusal to accept patients based solely on a diagnosis of HIV positivity or AIDS.*

- *enforce the existing state and federal laws against discrimination on the basis of HIV disease.*

GENERAL RECOMMENDATION

The state should:

- *initiate these recommendations and suggested mechanisms for the HIV/AIDS population as a pilot project, which then can be utilized for other groups with similar housing issues.*

PEDIATRIC, ADOLESCENT AND FAMILY SERVICES

The majority of cases of HIV infection and AIDS in children in New Jersey is related to prenatal transmission. For this reason, in order to discuss HIV infection/AIDS in children, one must talk about the disease in the context of families. The state has a strong interest in

preserving families intact and believes that the ideal situation for a child is in his own home, then a home with another family member and if this cannot be accomplished, a foster home or transitional home which would eventually lead to a more permanent living arrangement for the child. This, in fact, is consistent with basic child welfare philosophy and practice as mandated in federal and State Statutes. These laws ensure that child welfare agencies and providers make every reasonable effort to prevent the separation of families.

Although the DYFS does not get involved with families solely on the basis of the presence of HIV infection, the disease in families does at times present formidable barriers to maintaining the child with the biological family. For example, a parent or parents may be HIV infected and too sick to care for the child, the parents may be missing or may have abandoned the child due to drug abuse.

The early identification of families at risk for HIV infection and subsequent screening of mothers and children is critical to initiating treatment as soon as possible. The recommendations focus on getting services to families affected by this disease, maintaining and stabilizing families whenever possible through the provision of supports such as homemakers, specialized day care, respite care and home nursing care; coordination of services and preservation of rights to privacy and confidentiality for families and children.

Families

RECOMMENDATION:

- *The state should ensure the provision of services for children within the context of the family, however that family is defined.*

IMPLEMENTATION STRATEGY:

The state should:

- *expand the ability of pediatric HIV treatment centers to provide family care. The fragmentation of the adult vs. child treatment systems causes logistical problems for families as well as for case managers.*

- *examine and develop ways to provide supervised housing for families with HIV. When infected mothers become sick, the whole family is disrupted. In supervised family housing, there exists the possibility of alternate caretakers for the child(ren) and disruption for the parents and children is less likely.*

- *expand the family resource center approach (e.g., The Family Place at St. Barnabas) to all areas of the state. The centers would be community based and ideally located in close proximity to each of the pediatric HIV treatment centers.*

- *examine and develop ways to provide financial assistance to relatives and extended families to enable them to care for children in the family with HIV.*

Early Identification and Screening

RECOMMENDATION:

- *The state should ensure more aggressive early identification of pregnant women and children at risk for HIV infection.*

IMPLEMENTATION STRATEGY:

The state should:

- *improve procedures to screen women at risk, particularly pregnant women, and should work to establish OB/GYN protocols for these women.*

- *initiate dialogue between the Department of Health, hospitals and DYFS to shorten the turn-around time of HIV test results for children so that those without intact families can be moved into alternative placements as soon as possible.*

- *facilitate the standardization of hospital screening of newborns at risk for HIV infection.*

Service Provision

RECOMMENDATION:

- *The state should ensure that children and their families receive the services to which they are entitled and that these services are family-focused, community-based and coordinated.*

IMPLEMENTATION STRATEGY:

The state should:

- *initiate dialogue aimed at allowing children under the supervision of the DYFS, into experimental treatment at the same levels as other children, and resolve the legal issues.*

- *coordinate state activities for children and families through the Department of Health. Personnel from other service providers would be available to that office to provide technical and programmatic input and that office would have ongoing contact with the community and advocacy groups, and would have decision-making authority in the area of services to children, families and adolescents.*

- *give this central office the authority to experiment with innovative combinations of housing and health care funding to create responsive, cost-effective services for children with HIV. The successes should be studied for application to other populations of children in need of services (e.g. children born addicted to drugs).*

- *create an ongoing "forum" (such as the Statewide Pediatric AIDS Committee) to allow for networking, input and information sharing among various community-based service providers and government entities.*

- *currently there are eight part-time pediatric nurses working within the DYFS who coordinate health care for high-risk children and families, including children and families affected by HIV. This service should be expanded to enable a pediatric nurse specialist to work in each of the 41 DYFS District Offices/and Adoption Resource Centers across the state.*

Confidentiality and Right to Privacy

The issue of confidentiality is complicated for children and their families under State supervision. Many children with HIV require placement in foster homes, often on an emergency basis. In addition, children with HIV who live at home, with relatives, in foster care, or in transitional homes, often have multiple caregivers through the provision of supportive services such as day care, homemakers, pre-school, or infant stimulation programs. A dilemma often arises between the "need to know" by a number of caregivers and maintaining confidentiality of the child and its family.

RECOMMENDATION:

- *The state should ensure that the right to privacy and confidentiality of children and families affected by HIV under state supervision is upheld.*

IMPLEMENTATION STRATEGY:

The state should:

- *develop and distribute a comprehensive document to instruct the public, caregivers and state employees of their responsibility to maintain the right to privacy and confidentiality of the records of children with HIV and their families.*

- *develop a protocol which defines who needs to know, why and when.*

SUBSTANCE ABUSE TREATMENT

Because the magnitude of New Jersey's HIV epidemic is related directly to intravenous drug abuse, the need for expanded availability of drug treatment services was briefly discussed. Within the Cabinet Advisory Committee, the only departments that are directly involved in this area are the Department of Health, which provides grants for substance abuse treatment and for HIV counseling and testing with drug treatment centers (these are addressed under the Department of Health section in this report), and the Departments of Education and Higher Education, which provide educational policies, guidelines and materials to elementary, junior high and high schools, and to colleges. These latter two departments also provide training for counselors, teachers, and other adults involved in the school systems.

The Committee did make one recommendation on this issue. There are more general recommendations related to substance abuse awareness in the Prevention, Education and Testing Section.

RECOMMENDATION:

- *The state should ensure that there are adequate numbers of substance abuse treatment centers and spaces to accommodate all who wish to receive the service.*

IMPLEMENTATION STRATEGY:

The state should:

- *initiate a needs assessment for the number and types of drug treatment slots needed, pursue avenues for adding spaces and ensure funding.*

SPECIAL POPULATIONS

The Committee discussed several populations with special needs: prisoners, women, and those who are mentally retarded or developmentally disabled or who require mental health services. Both prisoners and those individuals who require mental health or developmental services are vulnerable populations. They do not have the ability to make the choices that are available to the general community. They are dependent on others for health and safety, and may need special mechanisms to ensure their human rights. Women have been an overlooked population in a number of areas: in service provision, particularly for pregnant HIV-infected women, and for pregnant drug abusers; in the Centers for Disease Control (CDC) definition of AIDS and its associated use for eligibility determinations; in housing options; and in joint services for a woman and her family.

PRISONERS

The Department of Corrections has authority over all inmates of the state prison system, but there is disagreement over the extent of its authority over inmates in municipal and county jails. There is wide variation in HIV education, testing practices, provision of counseling and services, and retention of human rights within these systems. The recommendations of the committee encompass access to services, coordination of services and human rights.

Access to Services

RECOMMENDATION:

- *The state should ensure that prisoners receive the same services that are available to the general population.*

IMPLEMENTATION STRATEGY:

The state should:

- *pursue the voluntary entry of inmates into clinical trials with experimental drugs. The Department of Corrections has received approval from the Attorney General's Office which authorizes physicians to use "innovative or experimental treatment" as long as the inmate wishes to receive it and "in the physician's opinion it benefits the inmate."*

- *institute broad, voluntary testing of inmates, with accompanying treatment and prophylaxis. The Department of Corrections has drafted policy revisions to implement this change and is awaiting administrative approval and funding. Preliminary estimates indicate that an annual cost of $11 million would be incured if 60% of the base population plus new admissions in year one were tested and treated. The succeeding years' costs would hold at about the same level because of the need for repeat testing and CD4 counts, and the need for AZT, Pneumocystis carinii prophylaxis and other available therapies.*

- *establish an intermediate level nursing care facility for the correctional population, (to include all who need it such as geriatric inmates, inmates with AIDS in remission and others) at a community facility. This will require some "set-up" costs, but in the long run inmates would be moved out of an acute care setting to the nursing care level, which is more cost effective.*

Coordination of Services

RECOMMENDATION:

- *The state should ensure that standardized, coordinated services are available, and provided to all correctional populations.*

IMPLEMENTATION STRATEGY:

The state should:

- *pursue resolution of the Department of Corrections' authority over municipal and county jails, and initiate or continue dialogue to standardize testing, counseling and treatment of HIV-infected inmates at all facilities.*

- *coordinate an educational program between the Departments of Corrections and Health to be given to all inmates upon admission and discharge.*

- *coordinate efforts of the Departments of Health and Corrections to train and counsel inmates and their families in HIV awareness. A program to select, train and utilize inmates as certified HIV counselors could be implemented. This group of inmates could be used in educational programs for juveniles within the Corrections system, and their expertise could prepare them for employment opportunities upon release.*

- *review the procedures for medical clemency and resentencing, and ensure standardization and application of those procedures.*

Human Rights

RECOMMENDATION:

- *The state should ensure that the human rights of prisoners are not violated.*

IMPLEMENTATION STRATEGY:

The state should:

- *initiate review of procedures for maintaining confidentiality of inmate test results and records, and improve procedures where necessary.*

- *ensure that testing for HIV is done with informed consent, and that counseling for all inmates tested is provided.*

WOMEN

The only departments that have direct involvement in women's issues specifically are the Department of Community Affairs, through its Division on Women, and the Department of Health, through various initiatives. The other departments include women in general populations addressed as part of regular department activities. The recommendations were designed to address service provision and coordination.

RECOMMENDATION:

- *The state should ensure that services to women are coordinated at the state level, and that services for pregnant drug abusers are available.*

IMPLEMENTATION STRATEGY:

The state should:

- *encourage the Departments of Community Affairs and Health to coordinate their efforts to address women's issues, and particularly, to investigate the need for services for pregnant drug abusers. They should then initiate dialogue to provide necessary services.*

MENTALLY RETARDED/DEVELOPMENTALLY DISABLED/MENTAL HEALTH CLIENTS

The departments involved with these populations are the Department of Education, through its provision of education to children with special needs; the Department of Human Services, through its Division of Developmental Disabilities and its Division of Mental Health and Hospitals; the Department of Community Affairs, through the Office of the Ombusdman for the Institutionalized Elderly; and the Department of Health, through its rate-setting system, licensing and inspection of facilities.

The recommendations focused on human rights, education and HIV awareness, and outreach.

Human Rights

RECOMMENDATION:

- *The state should ensure that the human rights of HIV-infected members of these populations are not violated.*

IMPLEMENTATION STRATEGY:

The state should:

- *initiate a review of the extent of segregation, lack of access to educational opportunities and vocational opportunities within the institutions, and resolve problem areas.*
- *initiate review of procedures for maintaining confidentiality of resident test results and records; improve where necessary.*
- *ensure that testing is done with informed consent (either resident's or guardian), and counseling appropriate to the resident's level is given.*

HIV Awareness Education

RECOMMENDATION:

- *The state should ensure that these populations receive education on HIV/AIDS awareness at a level that they can understand.*

IMPLEMENTATION STRATEGY:

The state should:

- *initiate dialogue with administrations of the facilities to improve the dissemination of educational material on HIV/AIDS and infection control at a level that the residents can understand, monitor the compliance and the effectiveness of the material.*

Outreach

RECOMMENDATION:

- *The state should ensure that outreach efforts for these populations are adequate.*

IMPLEMENTATION STRATEGY:

The state should:

- *review the outreach procedures in place at these institutions, and, where necessary, initiate discussions aimed at improving them.*

PREVENTION, EDUCATION, TESTING

The issues of prevention, education and testing cut across all state departments. The authorities of the departments cover a wide range of populations, from education, counseling and testing of correctional populations to grant awards to other agencies for counseling and testing, to development of guidelines for educational modules for children.

The Department of Labor is concerned with the state worker and the worker population in general. Many businesses still do not have HIV-awareness policies or training in place. The Department of Personnel deals with the state worker population which, includes personnel based in Trenton as well as personnel in state-run institutions and in field offices.

The recommendations focused on improving the coordination and delivery of prevention, education and testing services for several different populations: state workers, workers in general, the aged population, pre-college students and college students.

STATE WORKERS

Coordination of Services

RECOMMENDATION:

- *The state should coordinate its prevention, education, and testing efforts for all state workers.*

IMPLEMENTATION STRATEGY:

The state should:

- *create an HIV Coordinating Council, with dedicated funds, to coordinate programs, information and policies across state departments.*
- *develop a statewide policy to cover exposure to blood-borne pathogens, universal precautions for state-employed health care workers, the utilization of Hepatitis B Virus (HBV) vaccine and continuing, updated education for employees.*
- *place state policies related to HIV/AIDS in a central repository at the Department of Personnel. This repository would also include information on services available.*

Delivery of Services

RECOMMENDATION:

- *The state should improve the provision of prevention, education and testing services to its employees.*

IMPLEMENTATION STRATEGY:

The state should:

- *aggressively promote the Employee Advisory Service (EAS) counseling and referral system for affected employees and their families, establish a vital, ongoing referral network, and ensure that the financial support for this Service is adequate and available.*
- *ensure that all state departments conduct HIV/AIDS-awareness training for all employees on a periodic (not a one-time) basis to include updated information, and, where appropriate, preventive awareness for spouses and significant others, for children ages 6-12, and for young adults ages 13-18. Specific training needs include confidentiality and lines of communication, access to counseling and testing, universal precautions, handling irrational and difficult clients and regular clinical updates for health care personnel in the State system.*

ALL NEW JERSEY WORKERS

Coordination of Prevention, Education and Testing Services

RECOMMENDATION:

- *The state should coordinate and improve its prevention and education services to all New Jersey workers.*

IMPLEMENTATION STRATEGY:

The state should:

- *create an AIDS Awareness Council of diverse membership with dedicated funds, to coordinate and plan policies and awareness programs on behalf of all New Jersey workers. The Council should include membership from government, business, labor, and the general public.*

- *set up a District Task Force within the Department of Labor's Labor Sectors, using clients interfacing with DOL's various divisions and programs, to participate in awareness training and other related issues. The divisions and programs include Unemployment Insurance, Employment Service, Vocational Rehabilitation, Workers' Compensation, etc.*

- *assist private sector business in developing and implementing policies on HIV/AIDS to include segments on testing, counseling, immunization (e.g., Hepatitis B vaccine), exposure, diagnosis, treatment and financing for services. Incentives for businesses to implement the policies should be explored (e.g. tax benefits).*

- *provide the private sector with training support from the Department of Labor for employees and their families, and develop community leaders from the Chamber of Commerce to serve as coordinators of such efforts. The Department of Labor could also serve as a liaison with union organizations in providing awareness seminars through union locals.*

- *include persons infected with HIV (who wish to do so) as part of a speakers panel on HIV/AIDS issues.*

AGED POPULATION

There is a need to address the situation of older people who act as caretakers of persons infected with HIV, or who are themselves infected. Very little information is geared toward that age group. The specific division in state government that deals with the older population is the Division on Aging in the Department of Community Affairs.

Delivery of Prevention, Education and Testing Services

RECOMMENDATION:

- *The state should improve its educational efforts for the older population.*

IMPLEMENTATION STRATEGY:

The state should:

- *develop and distribute educational materials and conduct, directly or indirectly, sessions directed toward older people--both persons infected with HIV and caregivers.*

SCHOOLS - ELEMENTARY, MIDDLE, HIGH

The State Board of Education has mandated a coordinated sequential elementary and secondary curriculum in HIV prevention education with instructional units appropriate to the age, growth and development, and maturity of the pupils. HIV instructional guides have been developed and distributed by the Department of Education. Instruction on HIV prevention is usually part of the family life education and substance abuse curricula. It may be taught at the junior high and high school levels by the school nurse, health education teacher or physical education teacher. Individual counseling may be done by substance awareness coordinators or guidance counselors. At the elementary level, family life is most commonly taught by the regular grade-level teachers.

Selection of appropriate curricula to comply with State Board of Education instructional mandates is the responsibility of local district boards of education.

This difference in authority limits the ability of the Department of Education to ensure the effectiveness of local school instruction in areas in which there is no standardized state testing program.

Delivery of Prevention, Education and Testing Services

RECOMMENDATION:

- *The state should implement programs to increase the quantity and quality of HIV prevention education at all grade levels for all school-age children in New Jersey.*

IMPLEMENTATION STRATEGY:

The state should:

- *investigate methods of implementing and ensuring the content of HIV/AIDS prevention instruction taught at the local school level in accordance with the State Board of Education mandate and Department of Education instructional guidelines.*

- *support the training of public and nonpublic teachers in HIV/AIDS prevention education, utilizing Department of Education instructional guides.*

- *support the training of the substance awareness coordinators already in place at the secondary school level in HIV/AIDS prevention education; guidance counselors, school nurses and school social workers should subsequently receive similar training.*

- *coordinate efforts between the Departments of Community Affairs, Health and Human Services to provide training and technical assistance to community-based organizations and youth corps agencies that provide services to out-of-school youth.*

The second recommendation focused on HIV-infected children and school attendance. The Departments of Education and Health have been working on revisions to the regulations for attendance at school of HIV-infected children.

School Attendance

RECOMMENDATION:

- *The state should ensure that children infected with HIV are able to attend school under the least restrictive conditions possible, and that the confidentiality of HIV-infected students is preserved to the greatest possible extent.*

IMPLEMENTATION STRATEGY:

The state should:

- *encourage the finalization of the cooperative effort of the Departments of Education and Health to revise the regulations for school children infected with HIV; then implement the regulations.*

COLLEGES AND UNIVERSITIES

The Department of Higher Education handles the affairs of three public universities, nine state colleges, and 24 independent, degree-granting institutions and 19 community colleges. The Department also provides funds directly for several on-campus programs designed to support the academic development of students. These programs also address relevant areas of student personal development, making them appropriate settings for HIV awareness education.

RECOMMENDATION:

Delivery of Prevention, Education and Testing Services

- *The state should strengthen provision of HIV-awareness education to all college students.*

IMPLEMENTATION STRATEGY:

The state should:

- *pursue dialogue on methods to directly involve college students in HIV/AIDS-awareness initiatives.*

- *support substance abuse/HIV program directors at the public colleges, which include Rutgers, New Jersey Institute of Technology, eight of the nine state colleges and 19 county community colleges which enroll 79% of the full-time undergraduates and 57% of all graduate and professional students. The directors will coordinate provision of student education, preventive programming, counseling, and policy development surrounding alcohol, drugs, sexuality and HIV. These professionals will unify student behavior change efforts, provide leadership for training of college faculty and staff, and maintain current expertise in the rapidly changing HIV/AIDS area. Funding of these personnel under a single line item would establish a basis for program reporting to the state. Resources needed for salary and benefits would be about $1.2 million.*

- *provide assistance and leadership to the independent colleges (24, with 19 percent of all students in the state) by supporting professionals to serve as consultants and "directors on loan" to these colleges. Independent institutions would participate through financial contributions to regional college consortia, with public funding providing a percentage match. The cost to the State of salary and benefits for six professionals, matched at 50% by the institutions, would be about $135,000.*

- *provide a small amount of additional funding to specific programs, including College Bound (nine grantees), the Retention Initiative Grant Program (10 awards), and the Educational Opportunity Fund Program (at 44 institutions), to provide HIV prevention education without diluting their primary purpose of academic development. The resources needed are estimated at $4,000 per institution, or $250,000 total.*

- *provide support for research and evaluation of HIV prevention efforts at New Jersey colleges and universities.*

- *support at least bi-annual anonymous behavioral surveys of college students on 10-20 of the college campuses in New Jersey to evaluate the impact of HIV awareness programs. The cost would be at least $15,000 for producing, mailing and analyzing such a survey, assuming that professional, statistical and general office support staff are already available.*

- *set aside money to support grants for research in New Jersey on HIV/AIDS issues. The Department of Health's Division of AIDS could be the center for a network of researchers to share information regarding sources of funding, current findings of common interest and interaction between researchers and practitioners. Grants should be given in diverse areas of investigation, such as behavioral outcomes, clinical issues, and educational, psychological and social issues. Grants should be given for studies of broad significance and for the evaluation of outcomes of programs conducted on a single campus. Through this mechanism, the state could identify preventive models worthy of replication.*

GENERAL FINANCE, COORDINATION AND HUMAN RIGHTS ISSUES

The following three issues--finance, coordination of services and human rights--may have been partially addressed in previous sections, as they cut across all issues in any discussion of the HIV/AIDS epidemic. Finance, that is, the ability of a person to pay for services and the collection of adequate dollars for services rendered, is one of the most basic problems that needs to be addressed. Within a discussion of finance are issues of insurance coverage, adequacy of rates and payments, stretching limited dollars available for health care, and coordination of reimbursement and funding streams. Coordination of services is another significant problem. One intent of this report is to focus on a continuum of care; that is, a smooth flow of services to a patient based upon the needs at any time. Needs may vary over a period of months or years. Coordination of services is essential to providing this continuum of care. Finally, human rights issues pervade any discussion of HIV/AIDS. Discrimination in housing, in the workplace, in public areas, in insurance availability and in the community have been wide-spread throughout the epidemic. Confidentiality of a person's medical record or of test results, or even of the fact of having taken a lab test, are basic rights which have even more importance when related to HIV infection, because of the stigma attached to it.

The Committee's recommendations focused on improvement and coordination of finances, coordination of services, and protection of human rights.

FINANCE

RECOMMENDATION:

- *The state should investigate methods of implementing adequate reimbursement, coordinating reimbursement and funding and providing coverage for more citizens of New Jersey.*

IMPLEMENTATION STRATEGY:

Adequate Reimbursement

The state should:

- *review rates and reimbursement policies within the Departments of Health, Human Services, etc. to coordinate and enhance reimbursement rates, where appropriate, based on the condition of the patient.*

- *investigate the possibility of bulk purchases of medication directly from the manufacturer by state departments for their programs. Initiate discussions with New Jersey-based pharmaceutical companies about this issue.*

Coordination of Reimbursement and Funding

The state should:

- *share interdepartmental funding initiatives for combined projects.*

Provision of Coverage for More Citizens

The state should:

- *initiate review of insurance purchase under COBRA, and address the problems arising from delays in Medicaid and Medicare eligibility for the general HIV-positive population.*

- *pursue dialogue on presumptive eligibility requirements for Medicaid, SSI, etc. A part of the dialogue should center on the problems arising from use of the CDC definition of "AIDS" for presumptive SSI eligibility. The definition generally excludes the conditions presenting in women, and may also exclude some children's conditions. In general, men aged 21 - 62 and women without families are also excluded.*

- *investigate the impact of insurance practices on the HIV-infected population of both carriers based in New Jersey, who are regulated by the Department of Insurance, and carriers not regulated by the Department of Insurance, but who operate in New Jersey.*

- *initiate review of resources, grants, and other funding sources to determine how to provide the most services with current funds. Some examples include shifting funds or providing services to more people at a lower funding level.*

COORDINATION OF SERVICES

RECOMMENDATION:

- *The state should initiate immediate strategies to coordinate services at the state level.*

IMPLEMENTATION STRATEGY:

The state should:

- *create a subcabinet level group to work on coordinating state services and policy initiatives. This group should function under the auspices of a cabinet-level member, such as the Commissioner of Health or the Attorney General; should be sustained by the state; and should be ongoing. It should also have access to an advisory group composed of HIV/AIDS service providers to advise the subcabinet group and the Division of AIDS on continuing needs and solutions to existing problems.*

- *initiate review of the existing methods of providing services to state employees who are exposed at work. A coordinated mechanism to handle counseling, testing, diagnosis, treatment, support, etc. should be developed. A unified plan for services for exposed state workers, with decision making for each area existing, if possible, in a single agency with a well-defined goal should be pursued.*

- *coordinate the efforts of DYFS and the Department of Community Affairs for appropriate housing services for HIV-infected families.*

- *coordinate task forces within the Departments of Human Services and Health, and any other departments that have multiple divisions dealing with HIV issues, composed of designated AIDS liaisons representing each division. The purpose would be to facilitate coordination of planning services to HIV-positive consumers of services; to help formulate and disseminate consistent policies and procedures; to establish a tracking/information system consistent with policies and procedures as formulated by DOH; to help develop prevention/education curricula targeted to special-need clients; and to assess the applicability of current DOH policies and procedures with regard to special populations who are diagnosed HIV positive.*

- *develop a mechanism to allow the Division of Mental Health and Hospitals input into the CN review process for AIDS-related facilities.*

- *initiate dialogue between physicians, between physicians in business and industry, and the State to share information and ideas.*

HUMAN RIGHTS

Much of the public policy debate surrounding HIV/AIDS has focused on individual/civil rights in counterpoint to the public health need for research, prevention and treatment of HIV infection. As a matter of public policy, we must be sensitive to the potential for unlawful discrimination against HIV/AIDS victims, and at the same time we should endeavor to strike a balance with public health concerns. The balancing of the health and civil rights issues is a primary concern which should be addressed and answered in order to provide policy guidance to those affected by the issues.

RECOMMENDATION:

- *The state should immediately initiate strategies to ensure that the human rights of persons infected with HIV are not violated.*

IMPLEMENTATION STRATEGY:

The state should:

- *convene a representative group to frame an answer to the question of balancing civil rights and health issues. The Department of Law and Public Safety would be able to bring together, in an expeditious manner, representatives of various interests, in that it contains the Office of the Attorney General, the attorneys who represent various Cabinet Departments, the Division on Civil Rights and the State Medical Examiner.*

- *initiate efforts aimed at increasing the public awareness level of the rights of persons infected with HIV.*

- *dedicate a small unit within the Department of the Public Advocate to perform AIDS education and litigation functions. A unit with two attorneys, three field workers and one secretary could handle information flow, provide support for staff attorneys, advance public awareness through public appearances and publications, and pursue litigation to combat AIDS discrimination in public accommodations, housing and employment.*

- *develop policies which will prohibit discrimination in or denial of AIDS/HIV-related support and medical services to individuals with a prior history of psychiatric hospitalization.*

THE DEPARTMENTS OF THE STATE OF NEW JERSEY HIV/AIDS ADVISORY COMMITTEE MEMBERS

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- *Bonnie Watson*
- *Jackie Grabine*

Department of Corrections
- *William H. Fauver, Commissioner*
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APPENDIX III

THE DEPARTMENT OF HEALTH HIV/AIDS ADVISORY COMMITTEE RECOMMENDATIONS TO THE COMMISSIONER OF HEALTH JANUARY 1991

ISSUE: ***MANAGED CARE***

BACKGROUND/DISCUSSION:

One of the characteristics of HIV/AIDS patients which makes them difficult to treat effectively is the rapidity with which their medical condition changes. The current health care delivery system concentrates too much on the place of treatment and too little on the unique needs of each HIV/AIDS patient. Patients for whom a well-developed referral network with accompanying payment streams does not exist will get the least consistent care in the present system. This is a major problem to patients with chronic diseases; for an HIV/AIDS patient who may lurch from one acute episode to the next, it could be fatal.

A managed-care approach seems to be the best way to deliver care to HIV/AIDS patient. It is difficult to administer at first, but over time would improve access not only to hospital services, but to other, customarily unaddressed needs such as housing, long-term social services, drug treatment services, and hospice services, among others.

Currently, the only steady funding streams for indigent patients are the Medicaid program and the Uncompensated Care Trust Fund. These systems have several drawbacks. They can be very limited in the scope of services they provide, and they are facility-oriented rather than client-oriented. Further, the Trust Fund encourages patients to use the most intensive health care, even though it may be the least appropriate and most costly.

This is a propitious time to capitalize on the dynamic health insurance/state budget issues and establish a managed-care approach to HIV/AIDS. The Garden State Health Plan is already operated by the Department of Human Services, and their experience with rate setting and actuarial modeling would be helpful in determining the costs of the program. A comparison of the amount of current health care expenditures in acute, long-term, and home health services for HIV/AIDS patients could be contrasted to the projected cost of benefits delivered by the managed-care plan. The key to establishing a successful program would be the accurate identification of the population to be served, and a use of a one-time comprehensive eligibility and medical evaluation of the patient.

Under this approach, all of the participants would have access, through one case manager, to a myriad of services, both medical and non-medical. For one fixed rate--determined by actuarial analysis--Medicaid could pay for hospital care, long-term care, Residential Health Care Facilities (RHCF) care, purely residential accommodations, medical day care, social counseling, and prophylactic treatment in a clinic setting. This approach would yield a cost savings by getting patients to the lowest appropriate level of care at the earliest possible moment, and by preventing unnecessary acute episodes due to the lack of prophylactic- or maintenance-level care.

Licensure standards for involved facilities must reflect the variety of modalities through which care would be provided. In fact, there would probably be services provided which are not at this time even regulated by the Department of Health. These licensure issues need not present insurmountable obstacles.

The single most important factor to be addressed is Medicaid's participation in the program. Medicaid has already broken ground in projects such as the home health waiver demonstration project, and, as stated previously, has managed-care experience with the Garden State Health Plan. Along with finding a provider to commit to this plan, a state amendment to the Medicaid program and the development of a capitation rate would be the most significant milestones for the project. Working out a single rate would in the long run actually be easier for Medicaid to administer because auditing the plan would be much less complicated. In addition to other advantages, it is important to note that since Medicaid would be a major payer, a large portion of the cost--about 50 percent--would be assumed by the federal government.

This sort of project lends itself well to the kind of working group that would meet the following criteria:

1. *The physical plant needed to serve as a core facility is or can be developed.*
2. *A joint venture by several participating community-based facilities.*
3. *Familiarity with the Medicaid program and other major health care payers.*
4. *Established links to the community, which will assist in utilizing resources without duplication.*

Given the variety of potential payers this project could actually result in cost savings, while improving the quality and appropriateness of care services.

RECOMMENDATION:

- *A comprehensive system of managed care should be developed.*

IMPLEMENTATION STRATEGY:

- *The State should take the lead in encouraging managed care by creating a demonstration project with a negotiated system and in a designated area.*

ISSUE: ***MINORITY HEALTH AFFAIRS***

BACKGROUND/DISCUSSION:

As HIV/AIDS continues to spread particularly rapidly in New Jersey minority communities it is becoming increasingly important that the State use minority-based community agencies that are familiar with, and culturally sensitive to, the individuals they serve. Many of the areas discussed below cut across Department of Health divisional boundaries and even those between state departments.

Grant-funding methods must be evaluated and efforts increased to identify and fund less traditional, community-based health organizations, services and health-education strategies that are more appropriate to the communities they are suppose to serve. Community-based centers generally are attractive because they can provide "one-stop shopping" for individuals with HIV/AIDS. Consideration should also be given to increasing funding to local health departments, since they often serve as primary providers to underserved populations. Grant-evaluation data should be analyzed to determine the actual impact that service delivery, education, and outreach are having on the HIV/AIDS epidemic in minority communities.

Outreach and education should also be increased in an effort to recruit and maintain a racially and culturally balanced professional staff, particularly in those programs which target high-risk minority communities. Available funds should be used to train and employ indigenous community health workers. These individuals can be very resourceful in capturing hard-to-reach clients in their communities.

Finally, coordination of services at all levels--intradepartmental and interdepartmental - is absolutely critical to addressing any major public health problem such as AIDS. The state's efforts must be focused on developing a collaborative environment that encourages all providers to participate, and that eliminates the current overly fragmented system.

RECOMMENDATION:

- *The State should establish better coordination of, and access to, HIV/AIDS services in high-risk minority communities.*

IMPLEMENTATION STRATEGY:

- *The Department of Health should increase its efforts to identify and fund community-based organizations providing HIV/AIDS services. A particular effort should be made to identify and fund less traditional community-based services and education strategies.*
- *Grants to these organizations and services should include a method for collecting and evaluating data so that their impact can be measured.*
- *The department should increase its efforts to recruit and maintain a racially and culturally balanced HIV/AIDS professional staff, particularly in those programs which target high-risk minority.*
- *Whenever possible, minority community health workers should be trained and employed. They will be particularly useful in finding and enrolling hard-to-reach clients.*
- *All HIV/AIDS-related activities should be coordinated at all levels; the current fragmentation of effort must be eliminated.*
- *Local health departments should be assisted in obtaining third party reimbursement for STD clinics.*

LABORATORIES

ISSUE: ***NEW AIDS DIAGNOSTIC METHODOLOGIES***

BACKGROUND/DISCUSSION:

The impact of HIV/AIDS on the citizens of New Jersey makes it imperative that its state laboratories are in the forefront of drug intervention therapy.

Drug Screening

The State Virology Laboratory is equipped to study the development of new anti-AIDS therapies both in vitro and in a clinical setting. Several new testing modalities are possible, including the use of molecular mutants for in vitro rapid screening and the SCID mouse model for in vivo testing.

Polyclonal Activation

A number of high risk individuals have extended periods of viral production without antibody conversion. This lack of immunologic response is thought to be due to a shutdown of the host's lymphocyte differentiation to terminal plasma cell and antibody production. These cells can be stimulated in vitro using mitogens to promote the expression of viral-specific antibody. This antibody can then be measured using standard screening and confirmatory tests. Unlike the methods previously mentioned this would incorporate a common screening and confirmatory procedure already available for antibody determinations. Once developed this methodology would be very useful in screening HIV negative high risk populations.

Blood Decontamination

Although spread of AIDS through blood units has been minimized, there is still concern about the possibility of spread during the "window" period. Blood unit additives which are virucidal and non-toxic to the recipient are one means of controlling this spread. Exotic drugs, herbal potions, medicinal plants and a variety of unexplored natural products offer new avenues of innovative methods for blood decontamination. Both light and UV photosensitizing drugs are another option for investigation.

AIDS-Related Infections

As the number of AIDS patients continually increases the burden of testing for and treating the infections associated with the primary disease becomes of paramount importance. Rapid diagnostic tests which can detect the presence of viral antigens and or specific antibody must be developed. This would include both the polymerase chain reaction and in situ hybridization for cytomegalovirus, herpesvirus, hepatitis viruses, other related retroviruses and bacterial and parasitic opportunistic infections.

Recombinant proteins can also be produced for use in generating monoclonal antibodies for specific diagnostic tests as well as carriers for drug therapies.

The diagnostic applications can be initiated within six months to a year, while the monoclonal studies will require one to two years. This is extremely important for the State of New Jersey. The state labs should expertise in PCR and new detection techniques.

Expanded Testing Activities

Workloads exceeding 250,000 serum and dried blood spot specimens/year could be processed and results reported electronically with state-of-the-art computerization and the use of a bar code system on submission forms. (Current laboratory workload is 95,000 specimens/year) This will expedite the receipt, testing, tracking and storage of data on all HIV specimens. This processing, which would take from six months to a year to implement, would improve testing service efficiency and decrease the turn-around time for screening and confirmatory testing. It is important that the State laboratories have equipment that is up to date and modern in order to do its job properly.

The diagnosis of HIV infection before the onset of specific antibody production or in the case of indeterminate confirmatory testing is an important consideration in developing a policy for AIDS. To this end the polymerase chain reaction (PCR) and in situ hybridization, sensitive and rapid techniques that will demonstrate the presence of a single viral marker in infected cells, would be used to retest individuals who had indeterminate results. The PCR testing could be started immediately, with the in situ hybridization technique being implemented in 3-6 months.

In the area of patient management, flow cytometry can detect unique markers on the surface of lymphocytes defining the subpopulations of helper and suppressor cells. These measurements give an accurate assessment of the AIDS patient's stage of disease. Early intervention and monitoring the progression of infection in asymptomatic HIV-infected persons depends on the availability of CD4/CD8 ratios. This can be correlated to the presence of viral antigens or antibody. Clinical specimens can be tested rapidly for monitoring patients in interventional programs.

RECOMMENDATIONS:

- *New HIV/AIDS diagnostic methodologies and anti-AIDS therapies should be developed and/or implemented in the state laboratories.*
- *The HIV/AIDS testing capability of the state laboratories should be increased.*

IMPLEMENTATION STRATEGY:

- *The Department of Health's Virology Laboratory should implement several new testing modalities such as the use of molecular mutants for in vitro rapid screening and the SCID mouse model for in vivo testing.*
- *The Department of Health laboratories should develop a screening and a testing methodology called polyclonal activation. This procedure stimulates HIV antibody conversion in some high-risk individuals who may be infected but have not yet developed antibodies to HIV which can be detected by common screening and testing methodologies. This methodology would therefore be very useful in screening HIV-negative, high-risk populations.*

- *Various substances and methodologies, with the potential to prevent the spread of HIV in blood during the "window period" (the time between HIV infection and the development of detectable antibodies) should be investigated. Those include non-toxic blood-unit additives, exotic drugs, herbal potions and medicinal plants, and ultraviolet photosensitizing drugs.*

- *The number of HIV-infected individuals and people with AIDS is increasing and more rapid diagnostic tests should be developed in, and used by state laboratories.*

- *State-of-the-art computerization and the use of a bar code system on submission forms should be used to expedite the receipt, testing, tracking and storage of data on all HIV specimens; this will increase the Department's HIV testing capacity from 95,000 specimens/year to 250,000 per year.*

- *The polymerase chain reaction (PCR and in situ hybridization HIV-testing methodologies should be utilized in state laboratories. These sensitive and rapid tests are particularly useful in retesting individuals with indeterminate HIV-test results.*

- *The HIV-Testing Unit of the state laboratories should be the central or region facility for the long-term monitoring of all HIV-positive New Jerseyans, through the use of flow cytonomy - a technique which can assess an HIV/AIDS patient's stage of disease.*

ISSUE: ***OCCUPATIONAL AND ENVIRONMENTAL HEALTH***

BACKGROUND/DISCUSSION:

There is a large population of New Jersey public employees who are potentially exposed to HIV as a result of their occupations. Some of the these occupations include: health care workers, emergency medical services personnel, fire and police officers, corrections officers, and teachers and social workers. Employees and employers in these occupations need to receive accurate information regarding the risks and methods for preventing exposure.

The Division of Occupational and Environmental Health, given adequate resources, could establish a mechanism for providing AIDS information to the occupational groups listed above on a priority basis. This would be accomplished by adding staff to the Public Employees Occupational Safety and Health (PEOSH) Program, Education & Research Project. The Education & Research Project would provide the following services to address this important occupational health issue:

An educational video which describes HIV risk and prevention information specific to NJ public employees. Emphasis would include means for complying with the "Blood-borne Pathogens" Standard (1910.1030) adopted under the PEOSH Act and enforced by the DOH PEOSH Program, as well as information regarding other resources available in the state.

An information bulletin outlining the information described above and distributed to potentially affected public workplaces.

The purchase of related videos covering universal precautions and other topics to be lent to employees and employers wishing to provide in-house educational sessions.

HIV-prevention seminars at public-sector work sites throughout the state which use all of the educational materials described above. The availability of these seminars would be advertised widely throughout the state and offered free of charge to any employer or employee group requesting one.

Follow-up consultation and technical assistance to employer and employee groups who have received this educational information, and to public employees/employers in need of related information.

The estimated resources necessary to accomplish these educational efforts, including personnel, equipment, operating costs and educational materials would be approximately $170,000.00.

RECOMMENDATION:

- *The State through the Division of Occupational and Environmental Health, develop a mechanism for providing AIDS information to the occupational groups on a priority basis, especially for health care workers, emergency medical services personnel, fire and police officers, corrections officers, and teachers and social workers.*

IMPLEMENTATION STRATEGY:

- *Develop an educational video which describes HIV risk and prevention information specific to NJ public employees. Emphasis would include means for complying with the "Blood-borne Pathogens" Standard (1910.1030) adopted under the PEOSH Act and enforced by the DOH PEOSH Program as well as information regarding resources available within NJ.*

- *Develop an Information Bulletin outlining the information described above and distribute to potentially affected public workplaces.*

- *Purchase related videos (covering universal precautions, etc.) for the purpose of lending to employees and employers wishing to provide in-house educational sessions.*

- *Provide HIV prevention seminars at public sector work sites throughout the State using all of the educational materials described above. The availability of these seminars will be advertised widely throughout the State and will be administered free of charge to any employer or employee group requesting such.*

- *Provide follow-up consultation and technical assistance to employer and employee groups who have received this educational information, and to public employees/employers in need of related information.*

ISSUE: ***FAMILY SERVICE CENTERS***

BACKGROUND/DISCUSSION:

HIV-and AIDS-related community services are presently fragmented and difficult to access. Family Service Centers would provide a comprehensive array of these services in one location. (Family is be defined here in its broadest sense; that is, as the maintenance of those whose presence is significant to the client, irrespective of biological ties or legal relationship.)

The centers would combine medical, reproductive health, and social services for HIV-infected families, women and HIV-infected children in a single "one-stop-shopping" site and be linked to a tertiary service provider. Families should be transferred from hospital-based facilities to community-based centers/or private practices whenever possible. A single case manager should be assigned to each family, removing barriers that often make it necessary for HIV-infected women to choose between obtaining care for themselves or for their children. Such centers are strongly recommended in "Generations in Jeopardy" and by the Women and AIDS Network. Protocols should be developed that enable primary care providers to provide ongoing care, with the family receiving tertiary review/assessment at routinely scheduled times throughout the year.

These centers should be developed as a county-by-county system supervised by the state, and would include related social services such as, welfare, SSI, Medicaid, DYFS, Food Stamps and WIC. It has been reported that HIV-infected women and children have difficulty in obtaining such services because the agencies providing them are scattered and maintain limited hours. A frequent reason for a woman or child missing an appointment for medical care is a conflict

with another appointment for welfare or food stamps or a similar service which has been scheduled at the same time. The service-center approach should minimize such conflicts.

RECOMMENDATION:

Family-Centered Health Care Services

- *Medical, reproductive health, and social services for HIV-infected families, woman and HIV-infected children should be combined in a single "one-stop shopping" site linked to a tertiary care provider.*

IMPLEMENTATION STRATEGY:

- *Family members with HIV/AIDS should be transferred from hospital-based facilities to these community-based centers, or to the offices of private practice physicians, whenever possible.*
- *Protocols should be finalized to assist primary care professionals in providing ongoing care; families should receive condition assessments at routinely scheduled times throughout the year.*
- *Centers should include not only medical services, but as many related social services as possible, including DYFS, WIC, SSI, Medicaid, welfare, and foodstamps.*
- *To avoid duplication and gaps in services, a single case manager should be assigned to each family.*

RECOMMENDATION:

Family-Centered Health Services - Case Management

- *A community based case-management system, capable of providing health and social services to all members of a family, should be established.*

IMPLEMENTATION STRATEGY:

- *A family case-management system should be located at primary care facilities which are not necessarily AIDS/HIV provider sites.*
- *Local health departments and community based organizations should be considered for suitability as sites for this case-management system.*
- *In order to maximize federal matching funds, the Medicaid system should have a "case management" reimbursement code, which only certain providers can bill (e.g. local health departments).*

ISSUE: ***PRIMARY CARE***

BACKGROUND/DISCUSSION:

Those communities with the highest incidence of HIV infection also have primary-care access problems. Past experience shows, for example, that most women enrolled in case management through the Perinatal AIDS Prevention Project have no existing source of primary care. AIDS specialty services, such as TAP, do not have the capacity to be primary care providers for these women. Providing them with special services only for HIV-related problems will be of little value if they cannot access care for more basic medical problems.

The same problem exists for children with HIV infection. There are few primary-care providers at the community level. Children are forced to rely on primary care in those hospital-based settings which house the tertiary AIDS/HIV pediatric AIDS center.

The expansion of primary care can be accomplished in two complementary ways. In areas of high need but little availability of primary care, services should be funded at primary medical clinics already in place in these communities, such as Community Health Centers or Women's Health Centers with an expanded focus which includes care for the whole family.

In the rest of the state, training should be provided for primary care physicians, physicians' assistants, and nurse practitioners to enable them to care for the basic needs of individuals with HIV/AIDS. This is already being done in addressing pediatric AIDS, with the Regional Pediatric AIDS Treatment Centers actively recruiting and training community pediatricians and nurses to care for the day-to-day needs of HIV-infected children.

RECOMMENDATION:

Women and Families - Primary Care

- *Primary care for HIV/AIDS infected woman and children should be expanded.*

IMPLEMENTATION STRATEGY:

- *Services at existing clinics should be adequately funded.*
- *Services at existing primary medical clinics (such as community or womens' health centers) should be expanded and adequately funded in areas of high need for, but little availability of primary care.*

RECOMMENDATION:

Woman and Familes - Specialized Care

- *Specialized medical care services which treat women with a clinical diagnosis of AIDS should be expanded.*

IMPLEMENTATION STRATEGY:

- *The State should fund expansion of the Women's HIV services at University Hospital in Newark, and should invest in the development of similar clinics to serve women in the central and southern parts of the state.*

ISSUE: ***SEXUALLY TRANSMITTED DISEASE CLINICS***

BACKGROUND/DISCUSSION:

Treating HIV-positive patients in New Jersey's STD clinics is possible--and a good idea--but not feasible given present resource constraints. There are numerous obstacles which would have to be overcome prior to establishing such a policy. Some relevant issues, obstacles and problems follow.

Many STD clinics are not licensed to receive third-party reimbursement.

The laboratory support required by the present HIV treatment protocol developed by the Department of Health and the Medical Society is not presently available.

There is at present no capability to acquire or place high-cost medical equipment (such as X-ray) in STD clinics, and referral is not likely to be effective without outreach follow-up.

Clinicians will need to be trained in HIV-medical management. This could be done through the Department's Newark STD Prevention/Training Center, if the CDC approves. Traditionally, however, it has been difficult to attract qualified physicians and nurses into this area of medical care delivery. A "physician extender" law or waiver many be essential if these clinics are to be properly staffed.

STD clinics provide services for individuals with a high turnover rate, enabling them to screen large portions of a high-risk population. Any plan that will require patients to keep returning for care many times over the year could compromise the public-health-prevention aspect of these services by reducing the clinics' ability to see new patients.

Based upon past patient censuses and blinded seroprevalence studies, about 2000 to 2200 HIV-infected persons should be identified in the STD clinic settings. Once a person is identified as HIV-positive, approximately five visits per year would be required by each individual with CD4 counts of 500 or above, and approximately 13 visits a year for each patient with a CD4 count below 500. Given this, the present system would require an additional capacity for 10,000 to 29,000 patient visits--most of them in the high-incidence areas of northern New Jersey.

Even if STD clinics were only required to treat patients with CD counts above 200, service delivery will need to be considerably expanded. The method currently used for HIV counseling and testing in STD clinics will need to be streamlined so that virtually all patients are screened. If possible, a rapid HIV test which would identify infected clients while they are still in the clinic should be used.

Based upon estimates from the current treatment protocol, the cost of medical management of HIV-positive patients is expensive--approximately $9000 per patient. The treatment of 2200 HIV-positives in STD clinics would therefore require resources of up to $20 million. Even if the medical management of these ambulatory patients proves less costly, there remains a tremendous disparity between the resources needed and those currently available. There are also no additional funds available to purchase AZT or other therapeutic drugs from the current STD program budget. This gap cannot be made up by innovation and creativity alone; more dollars are needed.

RECOMMENDATION:

- *The ability of the state's sexually transmitted disease clinics (STD) to test for HIV and counseling and treatment for the HIV infection should be expanded.*

IMPLEMENTATION STRATEGY:

- *The current approach to HIV counseling and testing in STD clinics should be routinized and streamlined, with all patients screened for HIV.*
- *HIV/AIDS patients usually must return for treatment periodically. Because STD clinics generally see patients only once, they must be considerably expanded (25-65%, depending on patients' health status and HIV-infection prevalence); if this is not done, access to care by more traditional STD clients will be reduced and fewer high-risk individuals will be screened for HIV infection.*
- *STD clinics should treat HIV-infected patients who are relatively "healthy" (with CD4 counts of more than 200); those patients needing aerosolized pentamidine therapy should be referred to more appropriate medical settings.*
- *A "physician extender" law or waiver should be obtained in order to properly staff these clinics, as it has been difficult in the past to attract qualified health care professionals into this specialty area of medical care delivery.*
- *Present STD clinicians should be trained in HIV medical management; this should be done at the Department's Newark STD Prevention/Training Center. Approval from the CDC must be obtained, since federal funds support this training center.*

- *In order to test and treat HIV/AIDS patients, STD clinics must be supplied with certain medical equipment such as X-ray apparatus, and with laboratory support.*

- *Local health departments should be assisted in obtaining third party reimbursement for STD clinics.*

- *STD and HIV/AIDS outreach and counseling staff should be cross-trained and engaged in the identification and follow-up of high-risk sexual and needle sharing partners. High-risk individuals need to be made aware of their HIV/AIDS and STD-infection status and referred for appropriate treatment.*

ISSUE: ***SUBSTANCE ABUSE***

BACKGROUND/DISCUSSION:

(For the purposes of this plan, substance abuse is broadly defined to include heroin, cocaine, crack cocaine, other addictive drugs, and alcohol.)

The New Jersey HIV/AIDS epidemic is unique in the nation because nearly 60% of its 10,000 cumulative AIDS cases are related to intravenous drug use; it is, therefore, the state's primary mode of HIV transmission. Of the estimated 50,000 regular intravenous drug users (IVDUs) in the state (at least twice that number are occasional heroin users), approximately 6,000 are currently in treatment. An estimated 50% of IVDUs in the state's larger cities, including Newark and Jersey City, are HIV infected. A majority of the 31,217 adults incarcerated in New Jersey's correctional system are IVDUs, and HIV/AIDS has hit this particular population very hard.

Poverty, discrimination and rootlessness make drug users one of the most difficult populations to reach. Most IVDUs are heterosexual and sexually active; their sexual partners, many of whom are women of childbearing age, are also at risk. Nationally, 49% of women with AIDS have contracted it through heterosexual transmission; most of the children with AIDS in New Jersey became infected, directly or indirectly, through a drug-using parent. It should also be noted that in New Jersey minority women are disproportionately represented among women with HIV/AIDS.

Since 1982, New Jersey has consistently had more than twice the percentage of female AIDS cases when compared to the United States. This is attributable to female transmission from their own intravenous drug abuse - which accounts for 1,295 cases and is 64% of adult/adolescent female cases - and to women contracting the virus from their male sexual I.V. drug-abusing partners (602 cases or 30% of all female cases).

Among I.V. drug users, the utilization and sharing of contaminated "works"- needles and syringes - frequently leads to HIV infection, but New Jersey is one of only 11 states in which needles and syringes cannot be purchased over the counter. The legalization of over-the-counter purchase would allow drug treatment programs to purchase needles and syringes in bulk supply for distribution to I.V. drug abusers.

Effective drug treatment in New Jersey is synonymous with AIDS prevention. Drug treatment is a right and its denial constitutes a withholding of life-saving measures. Moreover, the total cost of drug treatment is significantly less than the cost of AIDS care. Outpatient methadone treatment, for example, costs between $2,200 and $3,000 per year. The costs of residential treatment range from $14,000 to $20,000 per year. On the other hand, the average lifetime cost of treating a person with AIDS is far greater than $60,000.

Despite these financial realities, the quality and quantity of drug treatment available in urban areas of the state is inadequate to meet current needs. In fact, since 1981, New Jersey's drug treatment facilities have been forced to charge fees due to cutbacks in funding. This has been an additional deterrent to users seeking treatment. The state's capacity to identify, assess and treat substance abusers must be increased. This can be done in a variety of ways.

Using existing facilities, the state could increase by 2,000 the number of methadone maintenance slots in existing major metropolitan programs. This could be accomplished within three months by expanding operating hours and hiring additional staff. Without copayment for indigents, the cost for this process would be about $6,000,000. This could be substantially met by initiation of a Medicaid reimbursement schedule that reflects the actual costs of treatment, and the institution of reimbursement from DEA.

It is also currently estimated that 1,000 patients are in need of intensive out-patient cocaine treatment in existing out-patient methadone and drug-free programs. Some of these patients could be enrolled in both methadone and intensive cocaine treatment. The cost is estimated at $2,000,000, much of which should be reimbursable. There would be a time frame of approximately three to six months for implementation .

Women-specific programming is very badly needed. It could be instituted in methadone and residential programs to provide culturally sensitive educational and therapeutic intervention as well as medical referral and linkage to needed social services. Out-patient programs could provide enhanced child-care services if space permits. The time frame for implementation of this process would be approximately three months, with a cost of approximately $1,000,000.

To cite one example of particular importance, there are simply not enough services available for drug treatment of pregnant women. In 1989, a joint Maternal Child Health Service/Division of Alcohol and Drug Abuse initiative resulted in the setting aside of beds in ten residential facilities in the state for the treatment of alcohol and/or drug addiction in pregnant women. In 1990 one outpatient drug treatment facility for pregnant women was set up with a grant from MCH, and three more clinics should be in operation by January 1, 1991. These services will not only help women reduce their chances of acquiring HIV infection, through drug injection or sexual activity for the purpose of obtaining, or under the influence of, alcohol and drugs, but will also reduce the occurrence of physical and emotional problems in children due to fetal exposure to HIV, alcohol, and drugs. It is clear that many more services are needed, since only about 200 women can presently be treated. One possibility might be for Medicaid to expand HealthStart codes to include a reimbursement code, as part of pregnancy services, for drug treatment and a new code for HIV testing and counseling/education.

Given the linkage of the HIV/AIDS epidemic in New Jersey with drug abuse, it would be advantageous for HIV testing and counseling as well as early intervention to be available on-site as an option for all methadone patients. The means of providing this service would vary depending on the program's size, needed space, reimbursement mechanisms, and availability of community health centers or hospitals that could co-locate services. Funding and time frames would therefore vary from site to site. Ideally, HIV intervention ought to be included in the context of primary health care.

It would also be advantageous to integrate substance abuse services into other facilities. Existing major infectious disease clinics and early intervention programs in hospitals and community health centers could have their own or co-located ambulatory substance abuse programs with methadone capacity, which would serve their patients or the parents of pediatric patients. Funding and time frames would again vary from site to site. It would also be beneficial for all programs in the Department of Health that serve high-risk families (TB, STD, Family Planning, Prenatal, MIH programs etc.), to have a substance abuse/HIV specialist on staff to provide staff education, patient consultation, assessment and referral.

This service coordination could also be enhanced by the creation of regional family services centers providing family-centered case management. These are discussed in more detail elsewhere in this plan. At such a center, every patient and family would be assigned a case manager. This system of case management would replace the multiple case managers currently attached to various projects, and would facilitate development of the county-by-county system suggested by the Community Advisory Group. Mental health services and support groups linked effectively to drug treatment and other support services are currently in short supply. There is also a lack of coordinated adult and pediatric primary care services for all family members, as well as TB and STD services and reimbursed family planning. Family service centers could help to remedy these deficiencies.

Housing for this population is discussed elsewhere in this plan.

RECOMMENDATIONS:

- *Substance abuse treatment - both inpatient and outpatient - should be available on demand.*
- *Legislation should be enacted to ensure that the full range of drug treatment is available for all who require the services.*
- *Demonstration projects should be established to test the effectiveness of needle- and syringe-exchange programs.*
- *Legislation should be enacted to allow for the over-the-counter purchase of needles and syringes.*
- *The state should create culturally sensitive and appropriate substance abuse programs designed to meet the unique needs of minority women.*

IMPLEMENTATION STRATEGY:

- *The state should expand inpatient substance abuse treatment programs for both adults and adolescents.*
- *The state Legislature should also appropriate $15 million to develop new outpatient drug-free, methadone maintenance and residential drug treatment slots and rehabilitation facilities for intravenous drug and other substance abusers. The State Department of Health should assist in the development and adoption of any necessary and appropriate regulations or legislation.*
- *The state should fund expanded substance abuse services for pregnant woman in residential facilities, and increased outreach for women and adolescents.*
- *The state should encourage the development of "drop-in" substance abuse treatment for those who wish to decrease their drug use over the long term, but who are not ready for short-term detoxification programs.*
- *The state should consider the creation of regionally-based comprehensive family service centers providing family-based case management.*
- *Joint ventures should be pursued to link services such as medical and social day care, respite care, shelter-provision, food vans, and clothing exchanges with drug treatment.*
- *The state should review existing regulations for both medical and third- party reimbursement for drug treatment services.*
- *Local general assistance programs should also be authorized to reimburse the cost of drug treatment.*
- *Medicaid reimbursement levels should be adjusted to cover the actual cost of drug treatment, regardless of the source of funding, until a larger, more comprehensive policy is developed.*
- *Comprehensive drug treatment coverage should be included in all new private medical insurance plans.*
- *Incentives should be developed and implemented to increase the medical, nursing and counseling personnel available for drug treatment.*
- *Executive and legislative leadership will be required to deal with not-in-my-backyard syndrome (NIMBY) in New Jersey.*

- *The Department of Health should develop needle- and syringe-exchange demonstration projects at selected geographic sites of high HIV prevalence in New Jersey. Access for successful programming, including expanded hours for obtaining services, should be included in any proposed demonstration project. An educational component, including education regarding proper use and distribution of condoms, as well as an offer of voluntary HIV testing, should also be incorporated. Serosurveys for research purposes could be conducted on returned needles and syringes to determine incidence.*

THE DEPARTMENT OF HEALTH
HIV/AIDS ADVISORY COMMITTEE MEMBERS

Office of the Commissioner
- *Commissioner Frances J. Dunston, M.D., M.P.H.*
- *Deputy Commissioner Richard Russo, M.S.P.H.*
- *Deputy Commissioner Leah Ziskin, M.D., M.S.*
- *Rosalind Thigpen-Rodd, Director, Minority Health*

Division of Alcoholism, Drug Abuse and Addiction Services
- *John Farrell, Acting Assistant Commissioner*
- *Joyce Jackson*

Division of Epidemiology and Communicable Disease Control
- *William Parkin, DVM, Assistant Commissioner*
- *Cliff Freund*

Division of Family Health Services
- *Susan Lenox Goldman, Acting Assistant Commissioner*
- *Dr. Alta Garfield*
- *Dr. George Halpin*
- *Barbara Kern*

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- *Pamela Dickson, Assistant Commissioner*

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- *Shahiedy Shahied, Ph.D., Assistant Commissioner*
- *Sam Thompson, Ph.D.*
- *Wayne Pizzuti*

Division of Occupational and Environmental Health
- *Rebecca Zagraniski, M.P.H., Ph.D., Assistant Commissioner*
- *Dr. Robert Boesch*

APPENDIX IV

PERSONS AND ORGANIZATIONS PRESENTING TESTIMONY AT PUBLIC MEETINGS

PUBLIC HEARING TESTIMONY

Newark

November 13, 1990

SPEAKER	***REPRESENTING***
1. *Caren Wiener*	*Union County AIDS Coordinator*
2. *Michael Steiner*	*Dr. John Thompech, Jersey City Medical Center*
3. *Barry Moore*	*National Association of Social Workers of N.J.*
4. *Rev. Peter Winstead*	*Council of Churches*
5. *Ellen Dryer*	*Straight and Narrow Medical Day Care*
6. *Julio*	*Person With AIDS (PWA)*
7. *Rosemarie Johnson*	*Person With AIDS (PWA)*
8. *Sylvia Contessa*	*Community Health Care of New Jersey*
9. *Karen Sofield*	*Person With AIDS (PWA)*
10. *Robert Maher*	*Saint Michael's Medical Center*
11. *David Byrns*	*New Jersey Health Officers Association*
12. *Derek Winans*	*Newark Community Foundation for PWAs*
13. *John Mavros*	*Joint Connection*
14. *Jim Davis*	*ACT UP/New Jersey Caucus*
15. *Jack Cox*	*Spectrum Health Care - Newark & Jersey City*
16. *Marc Lory*	*University Hospital - UMDNJ, Newark*
17. *Melvin Brice*	*Urban League of Essex County*
18. *Barbara Ford*	*AIDS Coordinator for the City of Newark*
19. *Janine Melly*	*Broughton House Program, Newark*
20. *Carolyn Brigham*	*Paterson Counseling Center*
21. *Michelle Housc*	*Person With AIDS (PWA)*
22. *Barry Godfrey*	*Person With AIDS (PWA)*
23. *Francis Blackman*	*North Jersey Medical Society*
24. *John Birmingham*	*Citizen*
25. *Richard Panzer*	*New Jersey Parent's Association*

PUBLIC HEARING TESTIMONY

Trenton

November 14, 1990

SPEAKER	***REPRESENTING***
1. *Larry Bacchi*	*Teachers Saving Children in Trenton*
2. *Carolyn Olynyk*	*Citizens Concerned for Life*
3. *Alda Atkinson*	
4. *Richard Smith*	*Parent/Citizen/Taxpayer*
5. *Joseph Mansfield*	*Private Citizen*
6. *Susan Wilson*	*New Jersey Network for Family Life Education*
7. *Edward Higgins*	*Statewide Association of Drug Treatment Centers*
8. *Katherine Pinneo*	*Family Planning Association of New Jersey*
9. *Ken Wogski*	*Southern NJ Chapter of the Association of Infection Control Practitioners*
10. *Mavina Williams*	*Visiting Nurses and Health Services - Union County*
11. *Michael Glenn*	*Private Citizen*
12. *Margo Churchill*	*Academy of Medicine*
13. *Terry Moore*	*Private Citizen*
14. *John Hansen*	*Handicapped Services*
15. *Laslos Sipos*	*ACT UP*
16. *Julio Salinas*	*Puerto Rican Association*
17. *Nancy Koenig*	*Diocese of Trenton*
18. *Elizabeth Degnan*	*Diocese of Trenton*
19. *Richard Cromwell*	*Diocese of Newark*
20. *Kelly Sheridan*	*AIDS Disaster Relief Bill*
21. *Linda Brunski*	*Private Citizen*
22. *Billie Jo Hawn*	*Citizen*
23. *Henry Stozek*	*ACT UP/N.J. Caucus*
24. *Katherine Neill*	*ACT UP Central Jersey*
24. *Jeff Van*	*Concerned Citizen*
25. *Dr. Loretta Jammott*	*Urban League of Metropolitan Trenton & Rutgers University*

PUBLIC HEARING TESTIMONY

Camden

November 19, 1990

SPEAKER	***REPRESENTING***
1. *Martha Chavis*	*Camden Area Health Education Center*
2. *Mr. Dudley*	*Concerned Parent*
3. *Mrs. Dudley*	*Concerned Parent*
4. *Dr. Jerome Platt*	*Division of Addiction Research UMDNJ*
5. *Lynn Brown*	*Planned Parenthood - Camden*
6. *Ann Katz*	*AIDS Coalition Southern New Jersey*
7. *Sebastian Porridge*	*ACT UP - South Jersey*
8. *Harry Morgan*	*Reality House*
9. *Bobbi Taylor-Foster*	*West Site AIDS Project - Burbank*
10. *Katie Leone*	*Coalition of AIDS - Passaic County*
11. *Marilyn Pinto*	*Family with HIV*
12. *Joanne Solos*	*CASA - Camden County*
13. *Dr. Ona Pela*	*Nigeria-America Institute on Substance Abuse*
14. *Ann Babcock*	*Red Cross HIV AIDS Center*
15. *Julianne Trinidad*	*American Red Cross, Camden*
16. *Mark Lyons*	*CATA*
17. *Joe*	*Concerned Citizen*
18. *Alison Bernstein*	*Person With HIV*
19. *William Cole*	*Gloucester County AIDS Task Force*
20. *Dr. David Candoluci*	*Southern N.J Treatment Assessment Program*
21. *Carol Degraw*	*Paterson Division of Health*
22. *Robert McEntire*	*Paterson Division of Health*
23. *Sandra Nillson*	*TAP Raritan Valley*
24. *John DuBois*	*South Jersey AIDS Alliance*
25. *Linda Boone*	*Joint Connection*
26. *Sharon O'Leary*	*Camden County Health Services*
27. *Ron Williams*	*Covenant House*
28. *Matthew McCrossen*	*Person With AIDS (PWA)*
29. *Dr. Cathleen Gekowski*	*UMDNJ - RWJ, Cooper Hospital, Camden*
30. *Calvin Wallstern*	*Dooley House, Camden*
31. *Beth Magee*	*Camden County Division of Health*
32. *Nicholas Piccone*	*Victory Subacute Care Services*
33. *Susan Bower*	*Cooper Hospital - Pediatric I.D. Center*
34. *Daniel Pichinson*	*Concerned Citizen*

PUBLIC HEARING TESTIMONY

New Brunswick

December 13, 1990

	SPEAKER	***REPRESENTING***
1.	*Terence Zealand*	*AIDS Resource Foundation for Children*
2.	*William Orr*	*North Jersey Community Research Initiatives*
3.	*Carl Sigmon*	*ACT UP*
4.	*BabEtte Pachence*	*Surgical Pathologist*
5.	*Marie Ransome*	*Concerned Women for America*
6.	*Rosemary Lyons*	*Problem Pregnancy Center*
7.	*Fred Mac Donald*	*Burlington Comprehensive Counseling*
8.	*Henry Van Arsdale*	*Movement Organized for Value Education*
9.	*Susan Fecko*	*Project Outreach*
10.	*Terri Leonard*	*Planned Parenthood, Middlesex*
11.	*Mark Candee*	*High Mountain Ministries, Inc.*
12.	*William Frankel*	*Clinical Psychologist*
13.	*Elaine Ehrlich*	*National Association of Social Workers*
14.	*Steven Marcus*	*NJ Poison Information & Education System*
15.	*Eileen Dyller*	*Planned Parenthood Association, Mercer*
16.	*Bill Stevens*	*Congregation of Christian Brothers*
		Middlesex County AIDS Coalition
17.	*Jennifer Schneider*	
18.	*Gilbert Baez*	*Treatment Assessment Program*
19.	*Wilma Sullen*	*New Jersey Association on Correction*
20.	*Joyce Hunter*	*New Jersey Association on Correction*
21.	*Joan Bottcher*	*Franklin Township Council*
22.	*Daniel Pitzhinson*	*ACT UP*

APPENDIX V

WRITTEN TESTIMONY

WRITTEN TESTIMONY RECEIVED

PERSON	ORGANIZATION
	Westside AIDS Project
	Coalition on AIDS in Passaic County
Barry L. Moore	National Association of Social Workers, Inc.
Linda L. Boone	The Joint Connection
Nicholas Piccone	Victory Subacute Care Services, Inc.
Ron Williams	Covenant House New Jersey
Julianne C. Trinidad	American Red Cross Camden
Henry G. McCafferty	Passaic Department of Human Resources
Andres Rivera	United Passaic Organization
Rev. Juan Andres Arroyo, Jr.	Smirna, Inc.
Greg Komeshok	Passaic Public Schools
	Continuing Education Division
Robin Burgos	Young Men's Christian Association
Lorenzo T. Hernandez	Hispanic Information Center of Passaic, Inc.
Susan Proietti	School Based Youth Services Program
Sister Jean Meyer	Holy Trinity School
Jill Beard-Cannady	Young Women's Christian Association of Passaic and Clifton
Wayne Alston	Passaic Community Action Program, Inc.
Elaine L. Nadel	Passaic WIC Program
Vrajesh R. Patel	Indian Youth Association
Carol Donkersloot	Guidance Guild Nursery School, Inc.
Mary Ann	Community Coordinated Child Care
Charlene L. Stokanerm RN	Coalition on AIDS in Passaic County
	Hemophilia Association of NJ
Gary L. Stein	Citizens Commission on AIDS
Parvin Saidi, MD	UMDNJ Hematology and Oncology
Caren F. Winer	AIDS Resource Foundation for Children
Diana Stager	NJ Hospital Association
Lawrence Bacchi	Teachers Saving Children, Inc.
Kathleen Sullivan	Project Respect
Susan N. Wilson	Rutgers NJ Network for Family Life Education
Katherine S. Pinneo	Family Planning Association of NJ
Kelly Shovidy	ACT UP
Dr. Jung H. Cho	Camden County Health Department
Martha Chavis	Camden AHEC
Anna Katz	AIDS Coalition of Southern NJ
Harry Morgan	Reality House, Inc.
	Westside AIDS Project
Lynn Brown	Planned Parenthood Camden
John S. Du Bois	South Jersey AIDS Alliance
David V. Condolucci, DO	UMDNJ TAP Clinic
Anne B. Babcock	American Red Cross Southeast Morris Chapter
	Nigeria-America Institute on Substance Abuse
	CAPCO-The Coalition on AIDS in Passaic County
William F. Bolan, Jr.	NJ Catholic Conference

PERSON	ORGANIZATION
C. Roy Epps	Civic League of Greater New Brunswick, Inc.
Delores Tyson	Planned Parenthood Essex County
Marc H. Lory	UMDNJ
Carl Sigmon	ACT UP
Br. Bill Stevens	Catholic Diocese of Metuchen
	Middlesex County AIDS Coalition
Rose Mary Lyons	
Linda Marotto	
Richard Biaz	Raritan Bay Medical Center
Ilene Dyller	Planned Parenthood Mercer Area
Steven M. Marcus, MD	NJ Poison Information and Education System
Dr. Ken Chance	UMDNJ
Frederic Sterritt, DDS	NJ Dental Association
William D. Fraenkel, Ph.D.	
Ellen S. Samuel	Planned Parenthood League of Middlesex County
Marie Ransome	Concerned Women for America of NJ
William P. Orr	North Jersey AIDS Alliance, Inc.
Sister Fran Demarest	St. Joseph's Hospital and Medical Center
Richard Panzer	Freedom Foundation of NJ, Inc.
Beth Magee	Special Child Health Services Camden County
Carol Dietler	Association for Retarded
	Citizens/Burlington County
Anthony Wingerter	Monmouth County
Sebastian Jeremiah Porridge	ACT UP/South Jersey
Kent Mast	Respect Incorporated
Carl Sigmon	ACT UP/New Jersey Caucus
Derek T. Winans	Newark Community Project for People with AIDS
	Community Health Care of North Jersey, Inc.
Mary G. Boland	Children's Hospital AIDS Program
Robert J. Maher	St. Michael's Medical Center
Yale S. Arkel, MD	St. Michael's Comprehensive Hemophilia
	Care Center
Albert D. Porter	M. L. King Academy for Youth and
	Community Outreach Center
Susan Preston	UMDNJ
Susan N. Wilson	Rutgers
Brenda Ripoli	NJ Nutrition Council
Audrey C. Burkart	Rutgers Cooperative Extension
Robert C. McCready	Mercer County
Rhonda Williams	DOA Testing & Counseling
Catherine E. Gavin	Camden County Health Department
Mary Therese Hynak-Hankinson	NJ Dietetic Association, Inc.
Alice Balamuth Wittsten	Bergen Department of Health Services
Marc H. Lory	UMDNJ
Carolyn Olynyk	Mercer Citizens Concerned for Life
Alda Atkinson	Mercer Citizens Concerned for Life
Gary L. Stein	Citizens Commission on AIDS
Nicholas DiMinni	Private Industry Council

APPENDIX VI

HIV/AIDS RELATED INFECTIONS - AN OUTLINE

HIV/AIDS RELATED INFECTIONS

HIV infection presents itself differently in different populations. The following is a list of symptoms and illnesses which may be linked to HIV infection should be investigated.

- *chronic pelvic inflammatory disease unresponsive to conventional therapy, including but not limited to repeated episodes of endometritis, salpingitis, tubovarian abscesses leading to multiple pelvic adhesions and chronic pelvic pain;*
- *chronic refractory vaginal candidiasis (thrush);*
- *chancroid, unresponsive to conventional therapy;*
- *anal, vulvar, or vaginal condylomas caused by human papillomavirus, unresponsive to conventional therapy;*
- *genital ulcers of undetermined etiology lasting for more than one month and unresponsive to conventional therapy;*
- *vulvar, vaginal, cervical and anal squamous cell neoplasias, including but not limited to disseminated or rapidly progressing squamous cell neoplasias of the lower genital tract;*
- *chronic, refractory urinary tract infections unresponsive to conventional therapy; and attempts to identify structural abnormalities;*
- *neurosyphilis, or definitively diagnosed reactivation of syphilis;*
- *renal failure with laboratory evidence of HIV and with exclusion of other causes;*
- *pulmonary tuberculosis;*
- *endocarditis, unresponsive to conventional therapy;*
- *neutropenia (non-ziduvodine related);*
- *bacterial and atypical pneumonias unresponsive to conventional therapy;*
- *chronic active or fulminent hepatitis;*
- *unexplained menstrual irregularities;*
- *recalcitrant and recurrent sinusitis, unresponsive to conventional therapy;*
- *relapsing or prolonged herpes zoster, less responsive to conventional therapy.*

APPENDIX VII

CURRENT NEW JERSEY HIV/AIDS BUDGET

FY91 BUDGET FOR HIV-RELATED SERVICES
DIVISION OF AIDS PREVENTION AND CONTROL
(In Thousands)

PROGRAM	PRIVATE $	STATE $	FEDERAL $	TOTAL $
Care and Treatment	$300	$ 8,176	$ 3,672	$ 12,148
Prevention/Educ.	–	$ 2,253	$ 3,173	$ 5,426
Epidemiological Services				
CAT/NAP	–	$ 2,014	$ 3,656	$ 5,670
Surveillance	–	$ 287	$ 522	$ 809
Medical Research	–	$ 401	$ 1,593	$ 1,994
Data Analysis	–	$ 177	$ 599	$ 776
Administration	–	$ 1,138	–	$ 1,138
				$ 27,961
TOTAL	$300	$ 14,446	$ 13,215	
GRAND TOTAL		$ 27,961		

* These dollars include grant money given to other divisions within the Department of Health, grants to other Departments, grants to outside agencies and operating expenses.

Category Costs	Dollars	% Budget
Grants	$18,212,000	67
Salaries (151 positions - 84 state, 67 federal)	5,248,391	19
Operations*	4,500,609	14
	$27,961,000	100

* Operations includes printing/supplies; telephone; postage; security; building maintenance; equipment; motor pool; etc.

FY91 BUDGET FOR HIV-RELATED SERVICES
NEW JERSEY STATE DEPARTMENT OF HEALTH
(In Thousands)

DIVISION	PRIVATE $	STATE $	FEDERAL $	TOTAL $
Laboratories	–	$ 121	$ 938	$ 1,059
Epidemiology	–	–	$ 1,677	$ 1,677
Occupational/Envir.	–	$ 11	$ 30	$ 41
Addiction Services	–	–	$ 2,231 ($45)*	$ 2,231
Community Health Services	–	$ 32*	$ 802*	$ 834
Pediatric AIDS Network	–	–	$ 979	$ 979
Perinatal AIDS Prevention	–	–	$ 900	$ 900
Maternal & Infant Health	–	$ 240 ($210)*	–	$ 240
AIDS Prevention & Control	$300	$ 14,204	$ 12,368	$ 26,872
				$ 34,833
TOTAL	$300	$ 14,608	$ 19,925	
GRAND TOTAL		$ 34,833		

* Federal and State dollars given by AIDS Division to other Divisions removed from AIDS Division amounts to avoid double-counting.

FY91 BUDGET FOR HIV-RELATED SERVICES
NEW JERSEY STATE DEPARTMENTS
(In Thousands)

DEPARTMENT	PRIVATE $	STATE $	FEDERAL $	TOTAL $
EDUCATION	–	–	$ 342	$ 342
CORRECTIONS	–	$ 8,150 (projected)	–	$ 8,150
HEALTH*	$300	$14,608	$19,925	$34,833
HUMAN SERVICES**				
DYFS	–	$ 1,228	$ 2,160	$ 3,388
Medicaid	–	$13,550	$14,850	$28,400
				$75,113
TOTAL	$300	$37,536	$37,277	
GRAND TOTAL		$75,113		

* Health includes Divisions of AIDS; Labs; Epidemiology and Disease Control; Occupational and Environmental Health; Addiction Services; Maternal and Child Health; Community Health Services.

** Human Services dollars do not include treatments and drugs/devices paid for by Medicaid (which may amount to about $20,000,000).

APPENDIX VIII

SUMMARY OF NEW JERSEY HIV/AIDS-RELATED STATUTES, REGULATIONS, AND PROPOSED LEGISLATION

SUMMARY STATUS OF HIV/AIDS LEGISLATION IN NEW JERSEY

Assembly Committees Key:
- AHH - Health & Human Services Committee
- AJL - Judiciary, Law & Public Safety Committee
- AED - Education Committee
- 2RA - Second Reading in Assembly
- AAT - Appropriations Subcommittee on Taxation

Assembly Bill #	Sponsor	Description	Current Status
A732	Smith, J./ Farragher	Requires the isolation of patients with AIDS in State psychiatric hospitals.	AHH 1/18/90
A800	Bush	Requires that cases of Acquired Immuno-deficiency Syndrome (AIDS) shall be reported to the Department of Health and provides for the confidentiality of AIDS patients' records.	AHH 1/18/90
A870	Villapiano	Requires hospitals to notify emergency medical transportation services providers that they are transporting a patient who has AIDS or AIDS related complex.	AHH 1/18/90
A971	Cohen	Makes knowing transmittal of AIDS a third degree crime	AJL 1/18/90
A1311	Crecco	Requires public school sex education and AIDS education programs to stress abstinence.	AED 1/18/90
A2035	Ogden	Requires health care facilities to notify first aid, ambulance and rescue squads that they are transporting a patient who has AIDS or a contagious, infectious or communicable disease.	AHH 1/18/90
A2211	Spadoro	Creates the AIDS Vaccine and Drug Research and Development Grant Program and appropriates $20,000,000.	AHH 1/18/90

Assembly Committees Key:
AHH - Health & Human Services Committee
AJL - Judiciary, Law & Public Safety Committee
AED - Education Committee
2RA - Second Reading in Assembly
AAT - Appropriations Subcommittee on Taxation

Assembly Bill #	Sponsor	Description	Current Status
A2554	Mattison	Requires hospitals to accept fair share of AIDS patients.	AHH 1/18/90
A3071	Bush	Amends reporting requirements of AIDS cases.	AHH 3/1/90
A3086Aca (1R)	Felice/ Haytaian + 3	Requires DOH to provide free AZT treatment to emergency volunteers diagnosed with AIDS or HIV infection.	AAT 12/6/90
A3772	Stuhltrager	Requires persons convicted of criminal offenses to be tested for AIDS in certain circumstances.	AJL 9/10/90
A3947	Bush	Prohibits discrimination against persons with HIV infection and AIDS.	2RA 12/6/90
A3948	Bush/Bryant	Makes various changes in AIDSreporting and testing requirements.	2RA 12/6/90
A3949	Bush/Felice	Requires AIDS testing for living donors of anatomical gifts.	2RA 12/6/90
A4022	Bush/Bryant	Provides for routine testing of newborns for AIDS virus.	AHH 10/11/90
A4303	Catania/ Zecker	Concerns testing of persons arrested or convicted of certain crimes for AIDS.	12/17/90
AR120	Ford/Doyle	Memorializes FDA to make certain drugs available for use by children with AIDS or HIV infection.	2RA 9/13/90
AR180	Bush/Felice	Memorializes Congress to pass legislation to provide additional funding for AIDS-related services.	2RA 12/6/90

Senate Committees Key:
SJU - Judiciary Committee
SIH - Institutions Health and Welfare Committee
SED - Education Committee
2RS - Second Reading in Senate
SLI - Labor, Industry and Professions

Senate Bill #	Sponsor	Description	Current Status
S163	Graves	Concerns testing of persons arrested or convicted of certain crimes for AIDS.	SJU 1/9/90
S611	Ewing	Requires physicians to report AIDS cases to local boards of health within 24 hours.	SIH 1/9/90
S613	Ewing	Requires person being tested for venereal disease to also submit to testing for AIDS, and requires applicants for marriage licenses to be tested for AIDS.	SIH 1/9/90
S615	Ewing	Requires inmates to be tested for AIDS infection and appropriates $95,000.	SIH 1/9/90
S624	Ewing	Requires testing of convicted persons sentenced to State prisons for AIDS.	SIH 1/9/90
S644	Ewing	Requires testing of all newborns for AIDS virus.	SIH 1/9/90
S804	Rice	Requires hospitals to accept fair share of AIDS patients.	SIH 1/9/90
S871	Rice	Requires persons convicted of certain drug offenses to be tested for AIDS.	SJU 1/9/90
S1444	Bassano	Establishes the New Jersey AIDS and Viral Disease Tissue Research Bank and appropriates $30,000.	2RS 12/3/90
S1586	Cardinale	Requires public school sex education and AIDS education programs to stress abstinence.	SED 1/9/90
S2003	Orechio	Requires Department of Health to supply certain information about AIDS and AIDS related complex to local health officers.	SIH 1/9/90

Senate Committees Key:
SJU - Judiciary Committee
SIH - Institutions Health and Welfare Committee
SED - Education Committee
2RS - Second Reading in Senate
SLI - Labor, Industry and Professions

Senate Bill #	Sponsor	Description	Current Status
S2136	Lipman	Requires that AIDS cases be reported to DOH and provides for confidentiality of records.	SIH 1/9/90
S2329Sa (1R)	Lipman + 1	Amends reporting requirements of AIDS cases and revised penalties for disclosure of confidential information.	AHH 5/17/90
S2854ca (1R)	Lipman	Requires informed written consent for HIV related testing; provides penalties.	2RS 12/10/90
S2933	Ewing	Requires a person charged with a criminal offense under certain circumstances to submit to an HIV test.	SJU 10/1/90
S3034Sca (1R)	Zane + 11	Requires applicants for marriage licenses to be tested for AIDS.	2RS 12/10/90
SJR2	Ambrosio	Calls for voluntary compliance in the workplace with AIDS "bill of rights" and requires various departments to report on AIDS policies and programs.	SLI 1/9/90

NEW JERSEY HIV AND AIDS-RELATED STATUTES AND REGULATIONS

1. N.J.S.A. 26:5C-1 et seq.

Sections 1 through 4 of the AIDS Assistance Act (L. 1984, c.126) were effective on August 8, 1984 and require the Commissioner of Health to establish programs to educate the public, including health care professionals, about AIDS. This public information campaign includes encouraging at-risk individuals to seek medical testing and counseling; as well as the establishment of a Statewide telephone hotline to answer requests for information and referral.

In accordance with this statute, the Commissioner of Health is given the authority to establish Departmental and local support programs to provide early detection, counseling, social services, and referrals for those who suspect exposure to AIDS.

The University of Medicine and Dentistry of New Jersey, in coordination with the State Department of Health, is identified to serve as a resource center and may offer diagnostic procedures, medical treatment, counseling, as well as any other services that may be necessary to assist AIDS victims and their families.

Sections 5 through 14 of the AIDS Assistance Act (L. 1989, c.303) became effective January 12, 1990. The additional requirements of the Act include the following major provisions:

- *All diagnosed cases of AIDS and HIV infection are to be reported to the Department of Health along with the identifying information of name, address, and social security number.*
- *Records containing AIDS or HIV identifying information are confidential and only able to be disclosed with a person's prior written consent, or by court order showing good cause in the public interest, or for an investigation of, or a prosecution of a first degree crime.*
- *Consent for the disclosure of a record of a minor is required by a parent, guardian, or other authorized individual.*
- *Violations may commence in a civil action including actual damages, equitable relief and resonable attorney's fees and court costs. Punitive damages may be awarded when the violation evidences wantonly reckless or intentional malicious conduct.*

2. N.J.S.A. 26:6-8.2 through 8.4

This law (L.1988, c.125) became effective on September 15, 1988 and requires that funeral directors be notified when a deceased person is infected with the human immunodeficiency virus (HIV), hepatitis B virus, or suffers from acquired immune deficiency syndrome (AIDS), AIDS related complex (ARC) or any of the contagious, infectious or communicable diseases determined by the Commissioner of Health. Violation penalties are up to $1,000.00 for each offense.

3. N.J.S.A. 10:5-1 et seq.

The New Jersey Law Against Discrimination provides equal employment opportunity for all persons regardless of race, creed, color, national origin, ancestry, age, marital status, sex, physical and mental handicap, nationally, atypical hereditary cellular or blood trait, or liability for service in the Armed Forces of the United States.

This statute prohibits discrimination against persons with disabilities in employment, public accommodations and real estate. The statute permits actions to be initiated either in an administrative forum or directly in Superior Court.

The Division on Civil Rights, the agency responsible for administering the State law, has taken the position that AIDS and perceived AIDS are within the scope of the statute. This position was upheld by the Superior Court in a March 12, 1987 opinion in Poff v. Caro, Superior Court of New Jersey, Law Division, Hudson County. In that case a preliminary injunction was granted in a housing discrimination case in which a landlord refused to rent an apartment to three homosexual men because he believed there would be a risk of the spread of AIDS.

4. N.J.S.A. 26:1A-7 and 1A-37

Under the provisions of these statutes the New Jersey Department of Health and the Public Health Council are given broad authority to protect the public health, safety, and welfare. Under this broad mandate, for example, administrative regulations such as N.J.A.C. 8:57-2, which follow, have been formally promulgated on the proper procedure for reporting diagnosed cases of AIDS and HIV infection.

5. N.J.A.C. 8:57-2

This Department of Health regulation was originally effective (as N.J.A.C. 8:57-1.14) on October 6, 1986 to address the reporting of AIDS cases with personal identifiers. On April 9, 1990 the Public Health Council broadened the current regulation to include the reporting of cases of HIV infection, without personal identifiers. This section of the regulation addressing HIV reporting became effective on January 1, 1991 and the Department of Health issued formal notification to all physicians and institutions on December 1, 1990. The regulation currently contains the following major provisions:

AIDS Reporting

- *AIDS cases are reportable directly to the Department of Health by physicians, superintendents of institutions such as hospitals, sanitariums, nursing homes, and penal institutions.*
- *The reporting is performed in accordance with the clinical criteria specified by the Centers for Disease Control.*
- *AIDS reporting includes the patient's name, address, municipality, county and state of residence, gender, race, birth date, the date of onset of illness, and such other information as required by the Department of Health.*

HIV Reporting

- *Every physician attending a person, or the person having control or supervision over any institution (hospital, sanitarium, nursing home, penal institution, or special facility testing for HIV) found to be infected with HIV report the following information to the State Department of Health within 24 hours of receipt of lab reports indicating HIV infection:*
  - *Physician's name and address, or address of institution*
  - *Patient's municipality of residence, gender, race, birth date, the date the specimen tested for HIV was obtained, and such other information as may be required by the State Department of Health.*
  - *The name, address, or telephone number of the person infected with HIV is not reported to the State Department of Health.*
  - *Clinical laboratories are required to report every three months to the State Department of Health the number of specimens tested for HIV infection, as well as the number of tests indicating infection.*
  - *The Commissioner of Health may designate anonymous HIV testing sites.*

6. N.J.A.C. 8:61-1.1 et seq.

This regulation addresses the attendance at school by pupils or adults infected by the human immunodeficiency virus (HIV). Pupils with HIV infection are not to be excluded from attending school for reason of infection unless the following exceptional conditions are evident as determined by the pupil's physician and/or the school medical inspector:

- *The pupil is not toilet-trained or is incontinent, or is unable to control drooling.*
- *The pupil is usually physically aggressive, with a documented history of biting or harming others.*

In the event that disagreement exists between the pupil's physician and the school medical inspector as to the existence of the excluding conditions, an evaluation of the pupil from a special Medical Advisory Panel established by the Commissioner of Health should be sought regarding the pupil's admissability in accordance with N.J.A.C. 6:29-4.4, which follows.

7. N.J.A.C. 6:29-4.4

This regulation details the procedures and instructions utilized by the Medical Advisory Panel, as mentioned above, when evaluating a potential case for exclusion from school attendance.

8. N.J.A.C. 8:61-2.1 et seq.

Through this regulation, which became effective on October 7, 1987, the New Jersey Department of Health utilized federal funding to initiate the Retrovir Drug Program. This program was designed to provide retrovir (Azidothymidine - AZT), or any other drug approved by the Federal Food and Drug Administration which has been recognized as prolonging the life of individuals with AIDS, to low income individuals who meet clinical and financial criteria. The program, currently called the AIDS Drug Distribution Program, has now been expanded to include two additional drugs--Alpha Interferon and Pentamidine. The program also provides the necessary medical equipment required to utilize Aerosolized Pentamidine.

9. N.J.A.C. 10A: Chapter 16-

This regulation was promulgated by the Department of Corrections and became effective April 6, 1987. It addresses all medical and health services in all correctional facilites within the State Department of Corrections, and, at Subchpater II, specifically delineates the criteria for the admission of AIDS cases to a Special Medical Unit. The placement of an inmate with AIDS into the Special Medical Unit takes place when the following criteria are met:

- *The condition does not require acute care hospitalization; but*
- *The medical condition of the inmate precludes housing in other medical units within correctional facilities of the Department of Corrections.*

APPENDIX IX

GLOSSARY OF TERMS

GLOSSARY OF TERMS

ACCAP (AIDS Community Care Alternatives Program) - A three-year renewable federal waiver program, prepared by Medicaid, which encourages the development of community-based services for people in need of long term institutional care. The purpose of the program is to help eligible individuals remain in, or return to the community, rather than be cared for in a nursing facility or hospital setting.

AIDS (Acquired Immune Deficiency Syndrome) - An acquired illness of the immune system which reduces the body's ability to fight special types of infection and cancers. The Human Immunodeficiency Virus (HIV), which is thought to be the cause of this illness, is transmitted through intimate sexual contact, in particular, anal and vaginal intercourse; direct exposure to or infection with infected blood or blood products; and from an infected woman to her fetus or infant. The data on oral sexual transmission are unclear. Once the immune system is impaired, persons who are diagnosed as having AIDS may easily develop one or more specific opportunistic infections or rare cancers which become life-threatening. Of persons officially diagnosed as having AIDS for three or more years, over 80 percent have died. Specific diseases must be present to be diagnosed officially as AIDS and to be reported to the Centers for Disease Control. In general, the diseases include unusual forms of bacterial, fungal and viral infections as well as rare cancers.

Anonymous Testing (see Testing)

Ancillary Services - Services other than direct medical intervention or care, such as X-rays, laboratory tests, respiratory therapy.

Antibody - Special protein developed by the body's immune system in response to exposure to specific foreign agents. A given antibody exactly matches the specific agent that causes an infection, much like a key matches a lock; the antibody then helps to destroy the infectious agent.

ARC (AIDS-Related Complex) - After being infected with the virus, some people may not develop the specific, life-threatening conditions used to identify AIDS. They may, however, develop other illnesses, and symptoms may include weight loss, chronic fatigue, lethargy, swollen glands, persistent diarrhea, low-grade fevers and oral thrush. Currently, it is believed that these conditions and symptoms may last for years, and a person may continue to have ARC without progressing to AIDS.

Asymptomatic - Without subjective or objective signs of illness. People who are infected with the AIDS virus (HIV), as evidenced by the presence of HIV antibodies, may show no symptoms of disease. Currently, scientists believe that 10-40 percent of persons who are infected with the HIV will develop AIDS within 5 years; approximately 25 percent will develop lesser forms of the disease; the remaining persons will remain asymptomatic for longer periods or indefinitely.

Blind Testing - The term blind (unlinked) testing refers to testing blood collected for other purposes (e.g. syphilis testing) for Human Immunodeficiency Virus (HIV) after removing personal identifiers (e.g. patient's name, precise address, clinic or medical record number). Minimum demographic information (e.g. sex, age, race) is retained to allow meaningful interpretation of results. Individuals do not know that they are being tested and the persons conducting the surveys have no means of linking test results to any individual. This is the only way to achieve an unbiased sample in a manner that is ethical and does not jeopardize confidentiality.

Blood/Body Fluid Precautions - *Special medical procedures taken to prevent infections transmitted by direct or indirect contact with infectious blood or body fluids. In addition to taking the appropriate infection control procedures, patients may be given a private room if their hygiene is poor. Masks need not be used; however, gowns should be used if it is likely that clothing will be soiled by the infected blood or body fluids. Gloves are used if the health care professional comes in contact with or handles blood or body fluids.*

Body Fluids - *Blood, serum, semen, vaginal or cervical secretions, vomitus, urine feces, saliva, cerebrospinal fluids, tears and drainage or oozing from burns, cuts, abrasions and infections.*

Case Management - *A system which coordinates, acts as a resource and links existing services to enable the client to navigate through the Health Care system and access services.*

CATINAP - *Counseling and Testing/Notification Assistance Program; programs within the Department of Health's Division of AIDS.*

CDC (Centers for Disease Control) - *A federal agency in the United States Public Health Service charged with the tracking and prevention/control of preventable disease.*

"The Commissioner" - *Refers to the Commissioner of Health.*

CBO's - *Community-Based Organizations*

Confidential Testing (see Testing)

Confirmatory Test - *A test that is more specific than a screening test used to determine the validity of a positive screening result (for example ELISA test). This may include a variety of procedures such as a Western Blot test, immunofluorescent antibody test, or radioimmune precipitation.*

Contact Tracing - *Public officials; 1) actively seek the names or trace the identity of persons who have come in contact with or have been exposed to a disease, and 2) actively notify these contacts concerning their possible exposure to the disease. Contact tracing is most commonly associated with certain contagious, highly infectious diseases, such as syphilis or other sexually transmittable diseases.*

Dental Dam (Rubber Dam) - *The rubber dam is a barrier device which protects the oral cavity of the patient from aspiration of foreign objects, application of topical medications and dental instrumentation; while providing the dental operator a dry, clean and aseptic field that enhances vision and eliminates interferences.*

Used to reduce the spread of HIV infection during cunnilingus and fellatio.

"The Department" - *Refers to New Jersey State Department of Health. (Also DOH)*

DOC - *Department of Corrections*

Designated Hospital Units for the HIV-Infected - *A specific section, wing or floor dedicated to a specific service.*

Detoxification - *A method of substance abuse treatment in which the person is freed of addiction by withholding drugs; sometimes referred to as "cold turkey".*

Diagnosis Related Groups (DRGs) - *New Jersey's system of prospective hospital payment, based on groupings of diagnoses, and average rates for each group for each acute care general hospital.*

Direct Cost of Care *- In this report, used to mean a.) the medical cost of care (physician, hospital, etc.) and the non-personal direct costs (blood screening, educational campaigns); b.) when used in reference to the DRG system, means costs associated with direct patient care (nursing, physician, lab, etc.).*

Doubling Test *- The period of time in which the number of cases of a disease doubles.*

DYFS (Division of Youth and Family Services) *- The division within New Jersey's Department of Human Services which handles children's issues, and administers children's services.*

Early Intervention *- Initiation of available treatment modalities in order to slow down the infection process. For example, persons with HIV could benefit from early therapy consisting of AZT, Aerosolized, Pentamadine or Bactrim.*

ELISA Test (Enzyme-Linked Immunoabsorbent Assay) *- A simple, rapid, sensitive blood test that measures antibodies to HIV proteins. The ELISA test was licensed by the Food and Drug Administration in 1985 to screen blood supplies only. As a blood screening test, the ELISA is highly sensitive and produces a small number of "false positive" and "false negative" test results. Because false positives are produced and the virus has a long incubation period, ELISAs are usually repeated if the first test is positive. If the patient tests positive a second time, then a more specific test, the Western Blot, is performed to confirm the results.*

Epidemiology *- The study of how disease or injuries are distributed in human populations and what factors influence this distribution. People who conduct such studies, known as epidemiologists, are concerned with: 1) how disease patterns change over time, 2) how disease patterns differ by geographic area; and 3) what personal characteristics influence the disease pattern. The personal characteristics of most interest to epidemiologists include basic demographic facts (e.g. age, sex, race, ethnic groups); biological factors (e.g. different blood characteristics); social/economic factors (e.g. income, education, occupation); and personal living habits (e.g. smoking, diet).*

Exposure *- When an individual has direct contact with HIV in a way that makes it possible to transmit the virus; however, it is not clear if everyone who is exposed to HIV will be infected with it. Generally, it is believed that numerous substantial exposures, such as a direct transfusion of contaminated blood or numerous sexual encounters through anal intercourse, are necessary or most efficient in transmitting the AIDS virus.*

False Negative *- When the test results from a diseased person fail to indicate the presence of the disease or condition. With HIV infection, a false negative occurs when an HIV-infected individual fails to test positive on any one of a series of HIV antibody tests--usually two ELISAs and a Western Blot.*

False Positive *- When the test results from a non-infected person indicate the presence of the disease or condition. With HIV infection, a false positive occurs when a non-infected person tests positive on a series of HIV antibody tests, usually two ELISAs and a Western Blot.*

Family *- Defined in the broadest sense as the maintenance of those whose presence is significant to the client, irrespective of biological ties or legal relationships.*

Family Service Centers *- Medical centers that combine medical, reproductive health, and social services for HIV-infected families, women and HIV-infected children in a single "one-stop-shopping" site and linked to a tertiary service provider. Families should be transferred from hospital-based facilities to community-based centers/or private practices whenever possible.*

Health Resources and Services Administration (HRSA) *- A federal agency which provides grant funds for the drug distribution program, case management, etc.*

High-Risk Behavior *- Behaviors that are known to be associated with transmission of the Human Immunodeficiency Virus from infected to uninfected persons. Common high-risk behaviors include sexual intercourse (especially anal intercourse) and, blood-to-blood contact (such as needle sharing by intravenous drug users.*

High-Risk Groups for AIDS *- Persons who have characteristics or behaviors that increase their chances of acquiring AIDS or HIV infection. Groups often noted as being "high-risk" or who practice "high-risk" behaviors include:*

- *Homosexual and bisexual males;*
- *Persons who inject drugs directly into their veins;*
- *Persons in countries where heterosexual transmission is believed to play a major role (Haiti/Sub-Sahara Africa);*
- *Male and female prostitutes;*
- *Sexual partners of persons in high-risk groups;*
- *Infants born to women in high-risk groups; or*
- *Persons receiving blood transfusions before 1985 when the screening for HIV antibodies began.*

Home Health Agency *- A facility which is licensed by the New Jersey State Department of Health to provide preventive, rehabilitative, and therapeutic services to patients. All home health agencies shall provide nursing, homemaker-home health aide, and physical therapy services in the patient's home or place of residence.*

Home Health Services *- A service which provides medical and domestic assistance, as needed, to maintain the client in his or her residence.*

Hospice Care *- An approach to treatment which recognizes that the impending death of an individual warrants a change in focus from curative to palliative care. A hospice uses an interdisciplinary approach to deliver medical, social, psychological, emotional, and spiritual services to make the dying individual as physically and emotionally comfortable as possible.*

HIV (Human Immunodeficiency Virus) *- The specific AIDS retrovirus which has been identified as destroying the body's immune system, making it susceptible to life-threatening, opportunistic infections or rare cancers the last stage of which is AIDS. The HIV is believed to be a relatively new virus. It is particularly resistant to treatment, as the HIV genetic material is incorporated into the healthy genetic material of the blood cells and is reproduced. Because the HIV genetic materials is reproduced, individuals who are infected with the virus remain carriers for the rest of their lives. The virus also has a long incubation period. Thus, it may be a long time between the point when a person is infected and when the antibodies can be detected (anywhere from three weeks to six months). It may also take from five years to ten or more before the disease becomes apparent and is diagnosed.*

HIV Infection *- Entry and multiplication of Human Immunodeficiency Virus (the AIDS virus) in blood and body tissues. This results in a transient or prolonged response from the immune system.*

HIV-2 *- A retrovirus, identified by the Pasteur Institute in Paris, which has currently been isolated among West Africans and a small number of AIDS patients in France, West Germany and Great Britain. The virus is capable of causing clinical symptoms that are similar to those found in patients with AIDS and related disorders. In spite of this, HIV remains the main cause of concern for public officials and the general public.*

Immune System *- A complex network of organs and cells that allows the body to defend itself against infections and substances which are foreign to the body.*

Incidence *- The number of new cases of a disease that occur over a specified period of time.*

Indirect Cost of Care *- In this report, used to mean a.) costs to the economy in terms of lost wages and future earnings due to premature disability and death; b.) when used in reference to the DRG system, connotes hospital costs not directly associated with patient care (e.g. administrative, housekeeping, capital costs).*

Informed Consent *- Documentation that a patient has been counseled by trained counselors about the positive, as well as negative, implications of undergoing a procedure and that the patient agrees, in writing or verbally, to undergo that procedure.*

Intravenous Drug User (IVDU) *- In this document IVDU refers to persons using/abusing illegal drugs.*

Latency Period *- The time period over which a disease exists without any symptoms appearing, or the time period from the point of infection to appearance of clinical signs of the disease. Based on current data, the latency period for the AIDS virus is estimated to range up to five or ten years.*

LAD *- Law Against Discrimination*

Local Rule *- The localization of final authority for implementation and administration of programs at the regional level, such as in city or county jails, in local school boards, or in individual colleges.*

Long-Term Care Facility *- A facility or distinct part of a facility licensed by the New Jersey Department of Health to provide health care under medical supervision and continuous nursing care for 24 or more consecutive hours to two or more patients who are not related to the members of the governing authority by marriage, blood or adoption; who do not require the degree of care and treatment which a hospital provides; and who, because of their physical or mental condition, require continuous nursing care and services above the level of room and board.*

Managed Care *- A system of care which is all-inclusive in the services it provides to the client.*

Medical Day Care Facility *- A facility or a distinct part of a facility which is licensed by the New Jersey State Department of Health to provide preventive, diagnostic, therapeutic, and rehabilitative services under medical supervision to meet the needs of functionally impaired adult patients who are not related to the members of the governing authority by marriage, blood or adoption. Adult day health care facilities provide services to patients for a period of time which does not exceed 12 hours during any calendar day.*

MH *- Mental Health*

Needle Exchange *- The process of receiving a clean, new needle for a used one. A major purpose of this process is to prevent the spread of HIV.*

Opportunistic Infections *- A variety of diseases that occur in individuals who do not have a healthy immune system. These diseases do not normally occur in otherwise healthy persons.*

Partner Notification *- Process of informing the sex or needle-sharing partner of a individual who is HIV infected.*

Pediatric AIDS *- Clinical AIDS in children under 13 years. Because more common or even rare congenital infections and congenital immune-related diseases must be eliminated as a cause of illness, a working definition of pediatric AIDS is open to more interpretation.*

Perinatal Transmission *- Transfer of HIV from the mother to the infant, either (a) through the placenta before the infant is born; (b) during the birth process itself; or (c) soon after birth through breast milk.*

Prevalence *- The number of people in a given population who have a disease, usually measured at a specific point in time. Prevalence includes both new and ongoing cases.*

Residential Health Care *- A facility which serves as a substitute for the resident's own home. It furnishes food, shelter, health care monitoring, and personal care to adults.*

RHCF *- Residential Health Care Facility*

Respite Care *- Support services which enable families to function as normally as possible by offering Home Care and Medical Day Care to assist the sick individual while the family member(s) are away.*

Risk Factors *- Any personal characteristic or behavior that increases the likelihood that a person will be infected by a given condition. The risk factors that are believed to increase the chances of transmitting HIV infection include engaging in intimate sexual contact (in particular, vaginal or anal intercourse) without a condom, sharing IV needles, and other activities which involve the exchange of infected body fluids. Co-factors are additional characteristics or other conditions that work with other risk factors to increase the chances of getting a disease. For instance, having a diagnosed sexually transmissible disease or already weakened immune system are believed to be co-factors or increase the chances of being infected with HIV or progressing to ARC or AIDS.*

Screening *- The process of identifying undetected disease (i.e. people who are infected but have no symptoms) by using tests, examinations or other procedures. These are usually simple, quick procedures that can be applied to large numbers of people. The tests are used to separate apparently well individuals who probably have a disease from those who probably do not. A screening test is not designed to diagnose a disease. It is important for persons testing positive on a screening procedure to be diagnosed and receive appropriate treatment, if necessary. Generally, screening tests are directed towards or used in populations considered to be at higher risk of contracting a disease. The ELISA test used to detect antibody to HIV is a screening test.*

Seroconvert *- When the status of a person's blood changes from seronegative to seropositive. Because it may take from three weeks to six months for HIV antibodies to appear, and thus for a person to seroconvert, it may be necessary to retest high-risk patients who originally test negative after this period of time.*

Seronegative *- The status of a person's blood when it is tested and the result cannot confirm that HIV antibodies are present. Generally, a person is considered to be seronegative if: 1) the initial ELISA is negative; 2) the initial ELISA is positive and the repeat ELISA is negative; or 3) both ELISAs are positive and the Western Blot is negative.*

Seropositive *- The status of a person's blood when it is tested and the results reveal HIV antibodies, as generally determined by two positive ELISAs and a positive Western Blot.*

Seroprevalence *- The relative frequency or number of individuals in a given population or community whose blood tests positive for an infection, in this case for HIV infection.*

Seroprevalence Surveys - A Seroprevalence Survey is a special epidemiologic method which uses samples of blood drawn from the general population or from special target populations to obtain unbiased estimates of the levels and trends of a certain infection, biochemical component or genetic characteristic. Unlike diagnostic tests which are performed on individuals with some evidence of disease, tests are applied to healthy people to determine current and past patterns of infection and disease. The blood results may be correlated with other characteristics of the population tested using demographic data obtained from questionnaires or records. Information from such surveys are useful to monitor trends in infection levels over time, to target populations for special interventions to prevent and control the spread of the diseases, and to evaluate the efficacy of prevention programs. Both blinded and unblinded testing approaches may be applied.

"Sex Worker" - One who provides sexual services for money; for example, prostitute, male hustler.

STD - Sexually Transmitted Disease

Sub-Acute Care (In Hospital) - Non-acute services; not as intense as one would expect in a hospital; more intense than can be provided at home.

Surveillance -The collection, analysis and interpretation of public health data. This is done systematically and on an on-going basis to study how disease occurs and spreads through the population. The data may also be used to help design programs to help prevent and control the spread of disease.

Symptomatology - Manifestations or signs of illness e.g., rash, discoloration or pain.

Testing - Using laboratory tests on an individual, case-by-case basis to screen for or to confirm the presence of disease.

> *Confidential - Personal identification of the individual such as name and street address are taken and become part of a record but the information given does not become public knowledge.*
>
> *Anonymous - No identifiers are given, not traceable*

T-Lymphocyte (T-Cell) - A type of white blood cell that is essential to the body's immune system in its fight against infection. T-cells help regulate the production of substances called antibodies. T4 lymphocytes are a special subset of T-cells. T4 cells start the body's immune response and help the body protect itself against viruses, parasites, tumors and fungi. The HIV virus interferes with the function of the T4 cells.

Transmission - The way in which a disease can be transferred from one person to another or in the way in which a person is exposed to the disease. HIV is transmitted in three main ways:

- *Through intimate, unprotected sexual contact: male to male and anal sexual intercourse are believed to be the most efficient means of transmitting HIV. Male-to-female transmission occurs, but less frequently. Female-to-male sexual contact is currently believed to be a less frequent means of transmitting the infection.*

- *Through parenteral exposure: through injections with contaminated or unsterilized needles. This primarily occurs with drug users who share needles when injecting drugs. Injection with contaminated blood products, through blood transfusions received before 1985, was also a route of transmission.*

- *Through perinatal transmission: transfer of HIV from the mother to the infant, either (a) through the placenta before the infant is born; (b) during the birth*

process itself; or (c) soon after birth through breast milk. Studies are still being conducted to see which mode of transmission occurs most frequently. Such information will help physicians decide the best way to care for pregnant women, new mothers and their infants who may be at risk for HIV infection. It is currently estimated that there is up to a 65 percent chance that an infected mother will pass the virus to her child. The risk for perinatal transmission is believed to be higher if the mother is, or becomes, seriously ill during her pregnancy.

TAP (Treatment Assessment Program) *- New Jersey's formalized early intervention program, which includes testing, monitoring, case-management, early intervention and prophylaxis. Implemented in five sites from October 1989 through April 1990.*

Uncompensated Care Trust Fund *- A fund comprised of the portion of the DRG rate collected from each NJ hospital bill for the purpose of covering the cost of hospital care for those who cannot pay. Hospitals draw from the Fund as necessary to cover care not paid.*

Universal Precautions *- A precautionary method used to prevent the spread of infection to either the patient or staff in a facility or service area. Universal means in this case system-wide. Encouraged in all facilities as a means of preventing identification with any particular disease or syndrome.*

Virus *- A type of microorganism that may cause an infectious disease. it can only reproduce in living cells, which it invades and then destroys as it multiplies.*

Western Blot *- A highly specific laboratory test that is used as a confirmatory test for HIV infection. It is able to identify and measure most, if not all, of the HIV antibodies in a blood sample. This more expensive test uses viral proteins separated by size that attach to the HIV antibodies in the patient's serum. It is used to confirm previously positive ELISAs' when patients test positive on the Western Blot, and it is assumed that they have HIV antibodies. However, there is no guarantee that the virus can actually be isolated from the blood; therefore, it is not always clear how infectious an antibody positive patient actually is or if he or she will progress to ARC or AIDS. In addition, laboratories using different chemical compounds or less stringent criteria when performing the Western Blot may produce more false-positive results.*

APPENDIX X

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BIBLIOGRAPHY

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